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Satisfaction with Treatment Decisions

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Introduction

The objectives of the research were to (1) develop an innovative CDSS that will enable women to integrate the information available to them, understand diagnoses, treatment options, and risks associated with treatment options, construct and structure their preferences, and make important health decisions; and (2) assess the impact of the new CDSS by making it available to women newly diagnosed with breast cancer and comparing it with existing technology (the Internet) and a control group in a carefully designed experiment. The assessment of the impact was made in terms of understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status and change in quality of life. Specifically, we compared two types of decision support technologies to a control group:

1. CHES: a new CDSS designed specifically to meet breast cancer patients' needs;
2. Internet: the rapidly proliferating Internet technology;
3. Control: standard patient education along with one of three books on breast cancer or a set of audiotapes produced by the National Coalition for Cancer Survivorship.

A. Background

Breast cancer affects one in nine women and is the second leading cause of cancer death among women¹. Understanding diagnoses, treatment options, their consequences, and risks are critical to making appropriate and informed decisions. The key problem, however, is that most women who are newly diagnosed with breast cancer are faced with making treatment decisions when they lack knowledge about the ramifications of their decision and the experience to deal with them. This problem is exacerbated by the fact that at the time of making decisions, most women are emotionally distressed, all of their options tend to have significant negative aspects, and the process of choosing a treatment option is usually confusing. Furthermore, because they are novices, women are not likely to have clearly developed preferences at the onset of a decision process, and their preferences are likely to change as they gather more information, thereby making the process of choosing among options even more difficult. In fact, some women may opt to let others make the decision for them, with the result that they may be less satisfied with decisions, more regretful, less compliant, and potentially less able to take charge of managing their health. This ultimately may lead to less optimal treatment options, and a loss in quality of life. Therefore, it is important to develop technologies that will help women to access, organize, process and integrate the wealth of information related to their decision. These technologies should be designed so that women can: (1) develop and shape their preferences based on a clear idea of the relevant issues and their implications; (2) make better, more informed, treatment decisions; and (3) take a more active role in managing their health.

Current research suggests that computer systems specifically designed to support people facing a life crisis can reduce these problems by giving users the flexibility to access information and support in quantities and at times of their own choosing. Such systems can empower individuals to take a more active role in their treatment decisions and to obtain the support they need at critical times, thereby reducing stress, increasing satisfaction and involvement in decisions made, enhancing recovery, and improving quality of life. Current information technologies, such as the Internet, can give access to information. However, such technologies typically provide users with little or no help to ensure that the important issues related to a specific problem, such as breast cancer, are covered. Few computer-based systems make comprehensive information on breast cancer available in an organized manner. The comprehensive health enhancement support system (CHESS) developed by the PI is one of them. Current computer-based decision support systems (CDSS) can assist decision-makers in evaluating well-defined options as long as these decision-makers are able to clearly state their preferences and have all relevant information in hand at the onset of the decision-making process. However, no technology has been specifically designed to address the evolutionary decision-making process faced by women newly diagnosed with breast cancer, a situation characterized by high emotional stress, lack of knowledge, large quantities of difficult information potentially available from many different sources, and unknown and/or unstructured preferences. Therefore, the objectives of this study were to:

1. Enhance CHESS to become a decision support system enabling women to integrate the information available to them, understand diagnoses, treatment options, and risks associated with treatment options, construct and structure their preferences, and make important health decisions;

2. Assess the impact of the new CDSS technology by making it available to women newly diagnosed with breast cancer and comparing it with other existing technologies and a control group in a carefully designed experiment. The assessment of the impact will be made in terms of understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status and quality of life.

While advances in early detection and treatment may reduce the probability of death from breast cancer, the impact on quality of life can be devastating. We use Cella's quality of life definition: "The broad-based assessment of the combined impact of disease and treatment and the trade-off between the two."² Quality of life issues take on particular importance and meaning as a result of a breast cancer diagnosis.^{3,4} Because the cancer is life threatening and its treatment disruptive and painful, both the disease and treatment can seriously undermine a woman's physical and emotional well-being as well as her ability to function in everyday life, and to maintain close family and social relationships. For younger women, it may also affect issues of child bearing and rearing. The problem is even more serious among African-American women, who have much higher fatality rates than Caucasian women following diagnosis of breast cancer.^{5,6} Poverty, discrimination, and different cultural attitudes among minority women create barriers to treatment and recovery. Research has documented problems of later detection due to access difficulties and attitudes that healthy people do not need exams^{7,8,9}; differences in treatment modality and quality¹⁰; and perceptions that death is inevitable so treatment is useless.¹¹ Thus an intervention that provides a practical way to improve quality of life is most needed by, and should have a larger impact on, low-income African-American women and potentially other low-income minority women as well.

Women faced with a life-threatening crisis such as breast cancer use multiple coping strategies to alleviate their stress. To the extent that these approaches either aid in solving problems or help to mitigate distress, they are positive mechanisms that can aid recovery.^{12, 13} Additionally, self-efficacy, or the perception that one's efforts can affect one's outcomes, has been shown to affect individuals' ability to engage in positive coping strategies.^{14, 15} In turn, positive coping strategies yield better health outcomes, greater efforts to improve functioning, and greater resistance to psychological dysfunction.^{16, 17} In order to engage in problem-focused coping around a breast cancer crisis, it is critical that women obtain and understand relevant information. A growing body of evidence suggests that information (e.g., what the experience will be like) leads to more accurate expectations¹⁸, improved health status, and increased longevity among breast cancer patients.^{19, 20} Women generally report that they want and value information.²¹ Our own surveys of women with breast cancer found that 10 of the 12 most important needs are informational requests.^{22, 23} However, providing that information can be complicated because individuals vary in the amount, type, and timing of the information they want and need to receive.²⁴ In one study, for example, only 30% of patients felt they received adequate information.²⁵ Our own studies and those of others also show that alternative forms of information such as talking with other breast cancer patients, and reading personal descriptions of their decisions, treatments, consequences and coping strategies can be particularly useful to patients.²⁶

In addition to information, women with breast cancer are faced with complex decisions involving uncertain outcomes, requiring them to collect, process and integrate complex information efficiently in the face of significant threat. Often they feel pressure (real or imagined) to decide quickly about issues they have never faced before.²⁷ In these circumstances, people under stress tend to reduce the number of options they examine, limit their information gathering, decide too quickly, and often regret their decisions.²⁸ In order to

meet their problem solving needs, it is important to provide a variety of options to fit the different problem solving styles individuals may adopt under these conditions.²⁹ For example, some may follow a structured process: learning about their options and potential criteria for weighing the alternatives, and then determining how important each factor is to them. Others prefer to ask advice from those who have been through the same experience, and still others prefer to have another person (e.g. the doctor) make the decision for them. Consequently, CDSS that provide information and support in multiple ways, some structured and some not, are likely to be more effective than systems without any structure or systems that provide only one structured approach.

In this particular research, we integrated both normative and new decision theories and designed a new CDSS that tries to provide timely, appropriate information to women with breast cancer, increase their understanding and knowledge, and provide them with a structured, yet flexible, framework to guide the entire decision process. This approach is consistent with what Keeney³⁰ proposes as developing *prescriptive* decision analysis: i.e., being concerned with helping people make informed, and hopefully better decisions.

A very important way individuals cope with a life crisis is to utilize social support. Nelles, et al³¹ suggest that social support provides three types of benefits: (1) Instrumental (providing goods and services), (2) Expressive (caring, listening), and (3) Information aid (education about the disease or its treatment). Research has found that social support enhances recovery from illness,^{32, 33} and patients satisfied with their social support tend to view their health more positively and report fewer physical symptoms.^{34, 35} Increased life expectancy has been noted in breast cancer patients with more extensive social networks,³⁶ and in women who attend support groups.³⁷

When women face breast cancer, their coping skills and consequent quality of life are enhanced by adequate access to information, social support, and problem solving aids. Home-based computer systems (such as the stand-alone CHESS and the Internet-based Breast Cancer Answers) offer the potential to meet these needs. The CHESS system, created by medical, communication, and decision scientists at the University of Wisconsin-Madison under the direction of Dr. Gustafson, is distinguished by its quality and depth, and its easy-to-use interface that is able to accommodate diverse learning styles.

Evaluation of CHESS impact on women with breast cancer indicates that CHESS can be an effective system to provide information and emotional support, and is widely accepted and used by both of these populations.^{23, 38-42} In particular, in two pilot studies of women with breast cancer in Wisconsin²³ and in Seattle (unpublished data), participants felt the discussion group provided a great deal of social and emotional support. All wished they had had such a program early enough to make surgery decisions. Neither age nor education has been found to be a barrier to CHESS use. Another study involving Medicare eligible women with breast cancer in southeastern Wisconsin³⁹ found that the older women, most of whom did not have a computer in their home prior to the study, used CHESS similarly to younger women in other studies. There were no differences in use between those who were 65-75 and those who were over 75. Cogent comorbidities did not appear to deter use. Another pilot study with eight African American women in impoverished areas of inner city Chicago found per capita use higher than with any other group (nearly 900 times in 15 weeks). Most women had no prior computer experience and some had no typing experience. Half had never completed high school. All were able to use CHESS.⁴²

B. Hypothesis/Purpose

The first year of the project was devoted to enhance the existing CHESS with easier user interfaces and expanded decision support to assist breast cancer women in accessing information, getting support, and making decisions. This enhanced CHESS is the new CDSS referred to in the original proposal. In years 2 and 3 we conducted a controlled experiment to compare the impact of the new CDSS and two other types of decision support systems with a control. In the fourth year we analyzed the data to evaluate and understand the relative impact of the new CDSS. Specifically, we compared two types of decision support technologies to a control group:

1. CHESS: a CDSS designed specifically to meet breast cancer patients' needs;
2. Internet: the rapidly proliferating collection of information and communication resources available to the general public;
3. Control:
 - a) an audiotape series produced by the National Coalition for Cancer Survivorship called Cancer Survivor Toolbox. This self-learning audio program is designed to assist patients diagnosed with cancer from the time of diagnosis through the rest of their life, or
 - b) standard patient education and any of the following books: *Dr. Susan Love's Breast Book*⁴⁸, *Celebrate Life*⁵⁴ (a book on breast cancer aimed specifically at an African American population), and *Breast Cancer? Let Me Check My Schedule*⁵⁵.

In this study, the new CDSS, enhanced CHESS, is a technology that provides all existing modules of the current CHESS as well as some new decision aids and also allows users to access the Internet. The CHESS system's strengths are: information tailored to the needs of breast cancer patients, ease of use and linkage between parts of the system, small and facilitated discussion groups, varied types of information (articles, personal stories, ask an expert, other discussion group members), enhanced credibility of Internet information through screening, and inclusion of decision aids.

CHESS is a system that can help people make important decision about their breast cancer treatment. While there are two tools in our service called "Decisions, Decisions" that are aimed specifically at helping women make decisions about surgery and other treatment options, CHESS as a whole can be viewed as a Decision Tool. For instance some women learn best by talking to others. Hence the Discussion Group service within CHESS becomes a crucial part of their decision support system. Others learn best by reading and thus Instant Library becomes an important part for them. Thus, since all aspects of CHESS can be important pieces in a woman's decision support system we have listed the enhancements that have been made to a number of the services within CHESS as well as overall design of the specific decisions support programs.

The original CHESS program included 12 services that approach a variety of breast cancer topics from different perspectives. *Questions & Answers* is a data base of short answers to common questions about breast cancer. *Instant Library* contains in-depth information from a variety of perspectives about breast cancer issues. *Getting Help* is a tutorial describing potential services and how to choose and benefit from them. *Referral Directory* is a database of national agencies that offer information, support, and referrals. *Personal Stories* are real-life accounts of persons who have struggled with breast cancer. *Dictionary* defines medical and technical terms in common English to enhance users' understanding. *Discussion Groups* allow users to use electronic bulletin boards to communicate with a professionally facilitated small group of others facing breast cancer (limited to less than 45 persons). *Ask an Expert* allows users to write and receive personal answers anonymously from a breast cancer expert.

Action Plan helps users identify barriers to implementing decisions and if possible plan to overcome them. *Profile* allows users to record their physical and emotional health, treatment history and plans, and demographic data. Experts can use this data in responding to “Ask an Expert” queries. *Health Charts* helps users track changes in their health and well-being, identify key concerns, and link them to relevant CHES material. Finally, *Decision Aid* built upon the principles of normative utility theory, helps users select criteria, weight them, and apply the criteria to selected options. (This module was redesigned as part of this study.)

A number of general improvements were made to the CHES system for this project including a new design and look. As a result of focus groups and user feedback, we also redesigned CHES to make it more user friendly and easier to access information. Navigation of CHES is now topic oriented (e.g. Surgery, Chemotherapy, Radiation,) as opposed to services oriented (e.g. Questions and Answers, Instant Library). In addition to the redesign we developed an online tutorial of how to most effectively use CHES. Again user feedback suggested that additional training would be valuable especially for those who have little or no computer experience. The online tutorial allows users to quickly and easily receive help specific to where they are in the CHES system. Improvements to CHES included a new way to navigate, categorizing services by areas, making templates for each CHES service, and developing a CHES logo. These graphic design changes were also incorporated in the support materials used in the study, such as the User Guide to CHES. The main goal of the design changes was to make CHES easier to use, particularly for those who have never used the Internet before, make the site more welcoming at first glance, and to add new capabilities to CHES such as streaming video. (Appendix # 1 – CHES Home Page).

Specific improvements or services added to CHES included:

1. Decision Notebook Service: This completely new service was developed for this project and for use in making three decisions that women with breast cancer are commonly faced with: Breast Surgery, Chemotherapy, and Joining Clinical Trials. Numerous interviews were conducted with women with breast cancer as well as focus groups to determine concerns women faced and what sorts of information they needed and wanted in the process of making their decision. The Decision Notebook:

- Describes the options (e.g. standard chemotherapy, chemotherapy clinical trial, no chemotherapy),
- Describes the Pros, Cons and Fine Print (or controversies) about the options
- Describes what criteria other women used while making their decision
- Allows women to rate the criteria against the options
- Links to detailed information specific to an option.
- Presents summary charts of the patient’s rating of the concerns and options
- Provides easy access to bookmarked items throughout CHES that the patient has marked and put into folders related to a specific decision (such as chemotherapy).

2. A second decision aid called “Learning from Others” was developed for those who prefer to learn in a more narrative style. Learning from Others covers the same material that is in Decision Notebook (such as concerns and options) but is presented in a narrative where a user can read the information in a more linear fashion. Learning from Others includes streaming video clips from women who have already made that decision. Learning from Others also has a direct link to go to the Decision Notebook.

3. Bookmarks were developed to allow the user to easily return to material in CHESS. The bookmarking function allows the user to tag a specific content in CHESS such as a Question and Answer, an Instant Library article, etc. The user can write notes about the information they tagged, and then can store that information in a number of folders (some of which are directly linked to the Decision Notebook). For instance, if a woman was reading an Instant Library article about the survival rates after lumpectomy and mastectomy, she could bookmark that specific article. She would then be given the opportunity to write a note about that article. In this case she may write that the 5-year survival rate is the same for lumpectomy followed by radiation as with mastectomy. The woman would then be able to put this into a folder called Surgery. When she goes to the Surgery Decision Notebook her bookmarked items and her notes will appear, as well as a direct link to that article.
4. A Diary service was added. This service allows women to write their thoughts about their breast cancer experience.
5. Discussion Group Archives: Some past discussions about breast cancer decisions are very valuable to new CHESS users. As a result we have created Discussion Group Archives. Users can review past discussions on several decision-related issues such as surgery, chemotherapy, etc.
6. Discussion Group Introductions was added to allow users to easily identify fellow users and know a little more about their history. Users fill out a form that includes items such as their breast cancer diagnosis and treatment history, other interests, etc. Whenever they send a message to the discussion group, an introduction button appears so that other readers can review their introduction.
7. Improvements to the Open Expert Messages in the Ask an Expert Service of CHESS. Over the years that CHESS has been available, hundreds of questions have been asked of the experts. Many of the answers (and questions themselves) would be of interest to other women facing breast cancer decisions as a result. Open Experts Messages was designed so that the experts can easily keyword an answer and transfer them to Open Messages that are accessible to all users. The Open Messages are now categorized by keywords to make them more accessible. Users are directly linked to the relevant Open Expert answers.
8. News Items was moved to have a more prominent place in the menu. Originally this service (designed to give users access to the latest news about breast cancer) was hidden in the Discussion Group section of CHESS. We moved it to the Services menu and have made it a direct link to the Breast Cancer Net newsroom.
9. Basic Web Skills was added as a CHESS service. This section of CHESS reviews the basics of searching the World Wide Web. The information and tips provided in this service are designed for people who are new to the Internet and perhaps even new to personal computers. In this service they learn the basic skills and information they need to move around the WEB.
10. Evaluating Web Info was developed and added as one of the Services within CHESS. This service is designed to help people understand how to be an informed WEB consumer. Users will learn the differences between .com, .edu, and .gov. They will also learn what questions to ask as they look at various sites, such as who funded the site, what are the credentials of the authors of the site, etc.

11. The CHESS Users Guide is a new service that was developed to help users to understand more about CHESS.

12. A direct link to the Medline Plus Breast Cancer site is now available through CHESS. The National Library of Medicine's MEDLINEplus information pages are designed to direct users to resources containing information about breast cancer. Users can search medical articles as well as connect to other government sites and resources.

13. Along with the daily operational tasks to keep CHESS running smoothly, continual development and updating of the material in CHESS was an ongoing focus of our work. An extensive review and update of all the CHESS informational services in the breast cancer module was completed. This review and updating included the following CHESS services: Questions and Answers, Instant Library, Consumer Guide, Resource Directory, WebLinks, and Decision Notebook, Learning from Others, and Video Gallery. Over 3,000 pages of content was reviewed and updated.

14. A new browser was developed specifically in this research for collecting use data. This browser is critical to understanding the use patterns of those involved in CHESS research. The Browser allowed us to capture where a person goes within CHESS and on the Internet, how they navigate, how long they stay at each page, and the amount of time it takes to download information once it is requested.

The aim of this research was to test the relative impact of these technologies. The impact consists of short term dimensions: understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, and desire to participate in decision. Longer-term effects consist of compliance with decision, change in health status and change in quality of life. Specifically, we tested the following hypotheses:

Hypothesis A: There will be a significant difference in quality of life among the technologies.

Hypothesis B: There will be a significant difference in understanding of diagnoses, treatment options, and risks associated with treatment options among the technologies.

Hypothesis C: There will be a significant difference in patients' desire to participate in their treatment decisions among the technologies.

Hypothesis D: There will be a significant difference in satisfaction with treatment decisions among the technologies.

Hypothesis E: There will be a significant difference in compliance with decision among the technologies.

The rationale for these hypotheses was that there were significant differences among the technologies in terms of (1) the amount of information available, (2) the way information is retrieved, (3) the degree to which information is linked, organized, and screened for the user, (4) the nature and existence of discussion groups and experts, (5) the ease of system use, and (6) the degree to which the presentation is personalized by the user. Thus, we expect there will be differences in the level of understanding, treatment decision satisfaction and decision involvement across technologies.

C. Methods

C.1. Description of the Interventions

C.1.1 CHESS

Subjects in the CHESS group were provided with a computer at home and were given access to the CHESS site as well as the Internet through the Web browser specifically designed for this study. A demonstration version of the CHESS breast cancer module can be found at <http://chess2.chsra.wisc.edu/demos/bc/home.htm>.

C.1.2 Internet

Subjects in the Internet group were provided with a computer at home and were given access to the Internet through the Web browser specifically designed for this study. In addition the Internet group was given a list of seven breast cancer internet sites and a brief description of each site (see appendix 2). The list of sites include the National Cancer Institute, Y-Me National Breast Cancer Organization, Oncolink, the American Cancer Society, the Komen Foundation, and Celebrating Life Foundation. The Internet group did not have access to the CHESS system and thus were not assisted in any systematic way in their information search and decision making.

C.1.3 Audio Tapes

Patients in the Audio Tape group were given a cassette tape player along with a set of Audio Tapes called the Cancer Survivor Toolbox. The set of six audio tapes were produced by the National Coalition for Cancer Survivorship, the Oncology Nursing Society, Association of Oncology Social Work, and Genentech BioOncology. The tapes covered the following topics; Communicating, Finding Information, Making Decisions, Solving Problems, Negotiating, and Standing Up for Your Rights. A booklet was included with the tapes that provided other suggested reading materials as well as phone numbers of National Organizations such as the National Cancer Institute, American Cancer Society, etc.

C.1.4 Book

Patients in the Book group were given copies of the following books; *Dr. Susan Love's Breast Book*⁴³, *Celebrate Life*⁴⁴, and *Breast Cancer? Let Me Check My Schedule*⁴⁵. *Dr. Susan Love's Breast Book* is a comprehensive book that is divided the following seven sections; 1) The Healthy Breast, 2) Common Problems of the Breast, 3) Diagnosis of Breast Problems, 4) The Causes of Breast Cancer, 5) The Diagnosis of Breast Cancer, 6) Treating Breast Cancer, and 7) Living with Breast Cancer. Susan Love, M.D., is an Associate Professor of Clinical Surgery at UCLA and director of the Revlon/UCLA Breast Center. *Celebrate Life* is a book on breast cancer aimed specifically at an African American population. *Breast Cancer? Let Me Check My Schedule* shares the stories of ten working women meeting the challenge of fitting breast cancer into their schedules.

C.2. Study Design

C.2.1 Recruitment and Training

The sample consisted of 307 women with breast cancer who were treated in one of four delivery sites. The delivery sites included University of Wisconsin Comprehensive Cancer Center (Madison, Wisconsin), Mayo Cancer Center (Rochester, Minnesota), University of Wisconsin-Milwaukee School of Nursing (Milwaukee, Wisconsin). One of the goals of the study was to recruit 100 African American participants. Since we did not get the number of African American participants that we expected from the University of Wisconsin - Milwaukee School of Nursing, we added Wayne State University in Detroit, Michigan as our fourth recruitment site. The sites were chosen because of their reported ability to recruit patients prior to surgery decisions. All of the sites were visited by the Principal Investigator.

The Project Director followed up the visits by the Principal Investigator with training sessions with each site coordinator. This included step by step review of the protocol (see Appendix # 3: Recruitment & Training Protocol), including recruiting study participants, the randomization process, installing computers (or other interventions), in-home training of study participants in use of the Internet and CHESS, setting up Internet Service Providers, documentation necessary for each study participant, removing computers, use data collection, as well as general study protocol.

Breast cancer patients were eligible for the study if they were within two months of their diagnosis, not homeless, able to give informed consent, able to understand and answer sample questions from the pre-test survey and not have a computer at home or use one at work. Doctors and/or their nurses introduced the study to patients at a clinic visit. A research staff member contacted the patient to tell them that we were evaluating various methods of providing information and support to women with breast cancer. After the study was described, those agreeing to participate signed a letter of consent giving us access to their medical records, allowing us to monitor their computer use (if so assigned), completed a pre-test survey and then were randomly assigned to the Internet, CHESS or the control group. This recruitment process led to 83% of those invited agreeing to participate. Patients who declined to participate did not differ from those who agreed.

Individuals randomized to either of the control groups were given the books or audio tapes immediately. Computer training and delivery for those randomized to the CHESS or Internet arms of the study were scheduled as early as possible (at the convenience of the subject). Study participants who had their own computer could use their computer if they preferred once data collection tool was installed. Internet connections and telephone line installation (if participants didn't have one) were arranged and paid by the project.

The Internet group received both written instructions on how to use the Internet plus a personal training program (average time 51 minutes) that covered how to use a computer, the basics of the Internet (what is it; how to get on to it; what is an Internet provider, a browser, a web page), showed them how to efficiently use the Internet (What is a browser? What is a hyperlink? How to move from one page to another? How to use the Back and Forward buttons, etc?) We also gave them addresses to a set of breast cancer Web sites that we considered to be high quality. These sites included NCI, ACS, Komen, Celebrating Life Foundation, Y-Me and Oncolink. We also provided them with a manual that covered the training material. Finally, we gave them addresses to a set of search engines and taught them how to use them. Follow-up training was available for participants who had trouble operating the computer.

The CHESS group received both written instructions on how to use CHESS and the Internet as well as a personal training program (average time 58 minutes) that covered basics of how to use the computer and the Internet but spent most of its time on how to use CHESS. See Appendix # 4: CHESS User Manual and Appendix # 5: Internet User Manual.

An 800 Help-line number was operated by project staff between 8AM and 5PM CST five days a week to help both Internet and CHESS participants with technical problems and questions concerning computers, modem connections, and the browser. At other times users could leave a voice mail message. Our staff checked for messages seven days a week and got back to users as soon as possible.

C.4 Measures, Data Sources and Instrumentation

Our main source of outcome information was patient report (using mail surveys). Four long surveys were administered -- one pre-test, one 2-month post-test, one 4-month post-test, and one 9-month post-test and three short surveys at 2, 4, and 6 weeks (all times are subject-specific). Copies of the PreTest, 2 week, 2 month, 4 month and 9 month surveys are included as Appendices # 6- 10. Subjects were paid \$15 for completing each long survey and \$5 for each short survey, a total of \$75 for completing all 7 surveys. Study characteristics (technology used, training information, set-up information, experimental group, start date) were entered in the recruiting records. The CHERS Web server automatically collected data on use of all CHERS services by CHERS study participants as well as use of Internet services by CHERS and Internet study participants. Specifically, CDSS use (Frequency, Duration, Component) was collected for each subject in the CHERS experimental group. These data permitted additional analyses to investigate the relationships between outcome variables and use patterns within this specific group.

The pre-test collected patient demographics (Age, Education, Ethnicity, Computer literacy, Cognitive style, Social Support, Location). The same information was collected again in the 2- and 4-month post tests in order to examine reliability of this information. All three long surveys collected information on health status and quality of life (Functional, Emotional, Social-family, Physical, Disease specific, Global).

Information and decision variables comprised the primary outcomes of interest in this study. These were measured in the 3 short surveys (to maximize the likelihood of asking questions regarding decision satisfaction right after a treatment option has been chosen) as well as in the first post-test. Specifically, we collected information to measure treatment option chosen (yes/no, which one), understanding of diagnoses, treatment options, and risks associated with treatment options, post-decision satisfaction (usability of information, adequacy of information, satisfaction with choice, and self-efficacy), amount of involvement in decision (desire to participate), decisional conflict (decision uncertainty, factors contributing to uncertainty), decision burden (difficulty, cognitive effort), confidence in decision, and compliance with decision. Satisfaction with choice, confidence in decision and compliance with decision require the subject to have chosen an option. Hence, the short survey was designed so that items not applicable did not need to be answered. Five previously validated instruments were used to measure all but the understanding of diagnoses, treatment options, and risks associated with treatment options and compliance with decision: the PDS scale ⁴⁶(10 items), the Decision Conflict Scale ⁴⁷(9-items). The Satisfaction with Decision Scale ⁴⁸(6-items), the Desire to Participate Scale ⁴⁹(1-item), and the Confidence in Decision Scale ⁵⁰(1-item). A new scale was developed and tested to measure understanding of diagnoses, treatment options, and risks associated with treatment options as well as compliance with decision.

C.5. Data collection

The site coordinators recruited subjects, administered the pre-test survey, and installed the computer. The pre-test administration occurred before randomization and took place when the patient agreed to participate in the study. Subsequent data collection used mail delivery. All surveys from all sites were mailed in pre-addressed and stamped envelopes to the Madison project office. To maintain a high degree of comparability in the mailed surveys, we carefully monitored individual timing in the study, and contacted individuals based on time-from-start rather than contacting all in the cohort at the same calendar date. Three days after a survey

was sent out, the study participant was called to make sure she received the survey and to encourage her to fill it out as soon as possible. If the survey did not come back within one week from the date it was sent out, a follow up phone call was made to remind the participant that we were waiting for their survey. If the survey did not arrive within two weeks of the date it was sent we called one last time and attempted to fill out the survey over the phone with the participant. If the study participant was unwilling to do this, or we were not able to reach the study participant we sent a duplicate survey along with a letter explaining that their survey data is critical to the research. If they did not return that survey no further follow up attempts are made. Our survey completion rate was 92%.

Because missing survey data would compromise our ability to analyze the data we sensitively pursued answers to all our questions. We placed particular emphasis on complete collection of all outcome measures. Surveys were entered into the database as soon as they arrived at the central office. If missing data were found, the Site Coordinators contacted the patient to attempt to collect the missing data. In the event that a small amount of data was still missing (e.g., when the patient could not decide what an appropriate answer would be to one question) we followed the advice of the Workshop on Quality of Life Research in Cancer Clinical Trials⁵¹ to decide on specific strategies to construct a summary score (i.e., add scores on the available answers and normalize). For missing questionnaires or interviews we documented the characteristics of the patient and included comparisons of those patients with compliers in the final report, describing as well why the questionnaire was missing. Because we included metastatic patients in our study, some women became too sick to use the computer. We attempted to collect all scheduled post-test data and we continued payment for survey completion unless the participant withdrew from the study.

C.6. Data Analysis

The data analysis for this project included several tasks. All study variables were further examined using univariate statistics. Descriptive statistics and distributions were examined for each continuous variable. Discrete variables were tabulated and those showing no or limited variability were transformed or dropped from the analysis. Because small numbers of very heavy users skew most measures of use, rather than dropping these cases, our statistical tests employed measures transformed by natural logs. However, all figures presenting use data display the original metric (e.g., minutes per week) for easier interpretation. For analyses comparing amount of use for all women assigned to CHESS and Internet groups (i.e., including zeros from non-users), analyses employed a 2 (between groups) by 8 (weeks, a repeated measure for individuals) GLM. For analyses focusing only on users, this repeated-measures model was impractical since most women were non-users during at least one week. Thus, we instead employed separate between-group F-tests for each week (or, when percentages were involved, separate chi-squares). Because there was no clear theoretical justification for predicting more use by one group than another, statistical significance is reported based on $p < .05$, two-tailed.

Because a breast cancer patient's quality of life is strongly affected by a number of demographic, living situation, and cancer treatment variables, outcome regressions reduced error variance by controlling race, age, education, whether they lived alone, had private insurance, breast cancer stage, time since diagnosis, and self-reported Karnofsky status (the latter omitted when functional well-being was the outcome because of overlap), as well as the pretest level of the dependent (two-month) variable for each equation. The latter covariate, of course, was by far the most important control in every case. Two sets of regressions were performed. In one, CHESS and Internet conditions were each contrasted against controls; in the other, CHESS was contrasted against the Internet. Because CHESS is a system designed

to produce improved status on these outcome measures, and has done so in previous research, statistical significance for comparisons between CHESS and the other conditions is reported based on $p < .05$, one-tailed.

Data collected on decisional aspects was extensive and consisted of the combination of existing scales as well as the addition of new items. Scales for these factors were created by taking weighted averages of the variables loading on each factor. For hypothesis testing, ANOVA was performed on each outcome variable of interest to test differences in the three experimental and control groups. These ANOVA analyses were performed for all outcome variables at each post-test measurement. Additionally, for some outcomes that were measured at several points in time, ANOVA analyses were also performed using differences in consecutive post-test measurements. To further test the hypotheses that the nature of differences among groups vary with background variables (demographics, treatment, comorbidities, etc.) as well as experimental/control groups, regression analyses were performed, regressing each decision outcome variable on all same covariates used for examining differences in quality of life along with variables controlling for experimental groups (by entering two dummy variables to represent the three groups in the regression equation).

D. Results

D.1. Pretest group comparisons.

Patient demographics, living situation, and disease and treatment characteristics were compared at pretest (Table 1). No differences between the three groups were significant¹, but a few were large enough to be worth noting anyway. The Control group had the fewest minorities, the CHESS group was most likely to be pre-menopausal, and the control group was least likely to be without private health insurance. In addition, the Internet group had a few more low-income women and the control group had the fewest women with college degrees. Meanwhile, the period of time between diagnosis and intervention was shortest for the Control group where there was no need to make logistical arrangements for installing and training on computers. As noted above, these differences are all controlled by entering the variables as covariates in subsequent analyses.

D.2. Use data comparisons.

Breast cancer patients in two of our three conditions had access to the Internet, and approximately half of those women also had access to CHESS. How - and whether - they used this new technology is a first step to looking at how they were helped by access to these technologies, but differential use patterns by these two groups are of interest as well.

Beginning by defining use by the number of times they logged on (separated by at least an hour), Figure 1 displays the average number of logins per participant (i.e., all participants, including those who never logged in during the 8-week period) over the first eight weeks in which they were on study. Clearly, both groups started out at around four to five logins per week and then gradually used less frequently over time, declining to around 1 ½ to 2 ½ logins per week ($F(7, 204)=11.11$, $p<.001$). Consistently across the eight weeks, the CHESS group logged in significantly more frequently than the Internet group, $F(1,210)=6.79$, $p=.003$. There was also some suggestion of a group-by-week interaction, $F(7, 204)=1.86$, $p=.08$, which is very likely the divergence in the two lines that appears at week 3: The CHESS users increased their logins between weeks 2 and 3, while the Internet users continue a rather sharp decline from the first week.

However, frequency of use may not necessarily capture effective use. One might well expect that a longer login offers more opportunity to learn, greater depth of thought, or other benefits. Thus, Figure 2 presents total time spent using the computer per subject for each of the eight weeks. The patterns here are similar to those of Figure 1, although the overall contrast between the CHESS and Internet groups was less pronounced. Use is initially heaviest, but declines steadily from about 115 minutes per week the first week to about 33 minutes the eighth week ($F(7, 204) = 11.41, p < .001$). The CHESS group used computer slightly but non-significantly more throughout ($F(1, 210) = 3.17, p = 0.08$), and the interaction of group and week was not significant, $F(7, 204) = 1.38, p = .22$).

Thus, from the first two figures, it is clear that both the frequency and amount of computer use were initially quite heavy but declined with time to levels that were nonetheless moderate and potentially important. It is also apparent that women who had access to CHESS logged in more frequently, although this did not produce as great a difference in total amount of time online.

One way to gain further insight into potential differences in how breast cancer patients use the Internet vs. a self-contained system like CHESS comes from looking at computer use of women who actually used the system, instead of the entire sample. First, we should say that the vast majority of women in each group eventually did log on to their computers. For both groups, an asymptote in the cumulative percentage using was reached by the fifth week, although slightly more women in the CHESS group ever used (91% vs. 83%). Figure 3 displays the percentages of women in each condition who actually logged on at least once in a given week, and again women in the CHESS group were more likely to log in each week (declining from 71% of the group the first week to 45% the eighth week, compared to 61% and 23% for the Internet group). Chi-square comparisons of weekly percentages were significant at $p < .05$ for all but the first and seventh weeks. However, when women logged on, the time spent per logon by the two groups was very similar (Figure 4), with the two groups never differing significantly. Thus, although a computer session seems to take similar amounts of time for women in the two groups, more women in the CHESS group were logging on.

Being online can mean many things, of course. Users could be shopping, playing games, reading news, searching aimlessly, or using email, and of course many were doing those things for much of their use time. Because our tracking system allowed us to see which websites were visited, we were able to categorize these sites into health and non-health related websites. Health websites included any site that had health content. Health-related URLs included CHESS (both the breast cancer module and those addressing other physical and psychiatric conditions: e.g., Alzheimer's, bipolar, depression, etc.), online drug stores and all information about medications, alternative medicine (including herbs and spiritually-oriented URLs on religion and horoscopes). Non-health URLs included all general information unrelated to health (e.g., law, travel, employment, finances, shopping); non-health related communication in chat rooms, email, messaging and electronic cards; searches not aimed at health topics, and entertainment (e.g., games, music, etc.). Given that the Internet group as a whole were somewhat less likely to use the computer at all, but that all these women were breast cancer patients, it was surprising to see in Figure 5 that they used non-health sites for significantly longer than the CHESS group each week ($p < .001$ for seven of the eight weeks). more overall ($F(1, 210) = 10.62, p < .001$). That is, of the time the Internet group spent online, much more of it was on non-health content. Although we would be cautious about entirely dismissing the potential value of non-health sites for breast cancer patients, this does make one wonder whether they were getting enough help dealing with their disease and its treatment.

This makes the comparison of health information (Figure 6) all the more striking, since it illustrates that CHESS users spent significantly more time in health-related websites (including CHESS) than did Internet users ($p < .001$ at each week). However, perhaps this latter comparison isn't entirely fair, since the CHESS system allowed easy and integrated access to health content, and the ease of use

could allow users to locate and browse services easily. To further examine this question, we redid the comparison ignoring all use of CHESS itself. That is, Figure 7 compares time spent using non-CHESS health URLs, to which both groups had equal access. Here, those among the Internet group who did use their computers (always a smaller percentage of the group than for CHESS, to be sure) did spend more time on non-CHESS health-related URLs than the CHESS group (significant at $p < .05$ except at week 5). However, after the first two weeks (roughly 55 minutes vs. 20 minutes), the differences are quite small. Thus, as in Figures 1 and 2, there is again a suggestion that the Internet group used up the readily locatable resources fairly quickly and after that found less disease-relevant information to use.

Overall, then, when breast cancer patients are given access either to the Internet or additionally to CHESS (a bounded, integrated system), those given CHESS are more likely to use the computer, use it more often and for longer times. In addition, those given CHESS focused more on health-related content, while the Internet group spent relatively much more time on non-health content.

D.3. Hypothesis A: There will be a significant difference in quality of life among the technologies.

Figure 8 provides an overall summary of the differences between the three groups. Since there are overall secular trends between pretest (usually within two months of diagnosis) and the two-month post-test (increasing scores on most measures, but lower on a few such as social support), the figure presents the amount of change as effect sizes for the CHESS and Internet groups, using the change for the control group as the zero point. Overall, the CHESS group improved more than the control group for four of the six outcome, while the Internet group improved less than the controls for five of the six. However, this summary takes no account of covariates and contains no tests for significance, and many of the differences are quite small.

Thus, despite the overall consistency of the pattern, the real tests of intervention effects are the multiple regressions. However, given the pattern in Figure 9, the larger differences tend to be those between the CHESS and Internet groups, and these will be the focus of the results that follow.ⁱⁱ Table 2 presents the betas and p-values for the CHESS-Internet comparison for each of the six outcome variables for the entire sample, and clearly there were no significant differences.

This is in striking contrast to previous studies of CHESS, but it is possible that difficulties recruiting sufficient subjects led us to accept participants less likely to benefit. That is, although our design called for recruiting women within two months of diagnosis, 20% were further along, a few as much as six months after diagnosis at recruitment. To test this, the right hand columns of Table 2 report the same analysis only for the 80% of the sample ($N=164$) recruited within two months of diagnosis, and a quite different picture emerges. Within this more appropriate sample, the CHESS group reported better social support, health self-efficacy, and functional well-being (all $p < .05$). Figure 10 further summarizes how the CHESS and Internet groups compared to the control group on these variables when covariates were adjusted for. In this case the CHESS group improved more or than the control group for all of the six outcomes, while the Internet group improved less than the controls for four of the six.

D.4. Hypothesis B: There will be a significant difference in understanding of diagnoses, treatment options, and risks associated with treatment options among the technologies.

Our measure of understanding was the patient's self-perceived knowledge of breast cancer and its treatment, which was included in Table 2 and Figure 10. There were, however, no differences between the groups in perceived knowledge.

D.5. Descriptive Findings about Decision Making Among Women Newly Diagnosed with Breast Cancer

In order to design more effective decision support systems, it is important to understand the types and timing of decision making. In this study, women completed brief surveys at 2-week intervals post-interventionⁱⁱⁱ to indicate which treatment and non-treatment decisions they had been considering during the last two weeks. The data resulting from these surveys provide a comprehensive overview of decision making by women who have been diagnosed with breast cancer. Although we refer to these surveys by the number of weeks post-intervention, the reader is advised that due to the voluntary nature of the survey submission, the interval between completion of surveys and the initial intervention date was not always precisely two weeks.

The first decision making question that study participants were asked addressed their desire for participation in treatment decisions. Overall, the proportion of women who preferred to share responsibility for making treatment decisions with their physician stayed relatively stable, varying only between 40 and 45% (Table 3), similar to the proportion who preferred to make their own decisions (with or without considering their doctor's opinion).

However, the finding reported in our earlier reports, that over the course of two months most subjects' desire for participation remained constant, did not hold true for the remainder of the study. In fact, the final results showed that half of all the women in the study changed their preferred decision making style at some point between two weeks and two months post-intervention (Table 4). Twenty-nine percent of the women in the study changed their preferred decision making style once while 15% changed twice and six percent changed three times. Of the women whose desire for participation changed over time, approximately the same numbers switched to wanting to make their own decisions versus those switching away from making their own decisions toward desiring more physician involvement.

Consistent with our preliminary findings throughout the project, as reported in Table 5, the number of treatment decisions considered by women with breast cancer decreased significantly from the 2-week post-intervention point to 2 months post-intervention from a mean of 3.5 (sd. 2.9) to a mean of 1.2 (sd 1.7). At the 2-week point, there was a significant difference ($F=5.67$, $p=.00$) in the mean number of treatment choices under consideration across the different intervention groups: women in the control group were considering more treatment choices (4.5, sd. 3.3) at the 2-week point than either women in the CHESS (3.2, sd. 2.5) or Internet (2.9, sd. 2.4) groups. By 2-months post-intervention, there was no difference between the number of decisions under consideration by women in the three intervention groups. The difference between the groups at 2 weeks post-intervention was likely due to the slight delay in providing interventions to women who were assigned to either of the two groups involving use of a computer. As discussed elsewhere in the report, the logistics of providing women with books or audiotapes were less complicated than providing access to a computer specifically set up for this study. In other words, breast cancer patients consider

ⁱⁱⁱ Although we refer to these surveys by the number of weeks post-intervention, the reader is advised that due to the voluntary nature of the survey submission, the interval between completion of surveys and the initial intervention date was not always precisely two weeks.

fewer choices as time since diagnosis passes, and the difference in how quickly the control group could begin the study is a confound that probably accounts for this difference.

At 2-weeks post-intervention, over 85% of the women in the study reported having at least one treatment choice under consideration. The mean number of treatment choices for these women was 4.2 (sd. 2.7) with significant differences across the intervention groups. By 6 weeks and 2-months post intervention, the percentage of women still considering at least one treatment choice was down to 53% and 52%. On average, these women (the 52%) were considering 2.4 treatment choices at the 2-month point with no significant differences across the intervention group.

These findings highlight the need noted in earlier progress reports regarding the need for providing timely decision support. Women who are diagnosed with breast cancer are faced with a number of significant treatment choices in a relatively short period of time and any delay in providing support that is intended just for decision making reduces the utility of such support. Of course, women who find themselves facing such a diagnosis need other types of support that go way beyond just decision support.

As Table 6 shows, the types of treatment choices that women with a diagnosis of breast cancer face go far beyond the well-known lumpectomy versus mastectomy decision. At 2-weeks post-intervention the most common treatment choice under consideration had to do with chemotherapy: whether to have chemotherapy, what type of chemotherapy to have, and/or how long to have chemotherapy treatment. Forty-seven percent of women were considering chemotherapy options at 2-weeks post-intervention. This was the most important treatment choice for one quarter of the women in the study at this point. The second most frequently considered treatment choice at 2-weeks concerned Tamoxifen. Four out of ten of the women in the study were considering Tamoxifen but only eight percent of the women considered this their most important treatment choice at this time. One in three subjects indicated that they were considering a choice between lumpectomy versus mastectomy over the first two weeks since receiving the intervention. Attempts to recruit women into the study as soon as possible after diagnosis were successful enough to reach these women who had not yet had surgery. Twenty-nine percent were also considering issues associated with lymph node sampling at 2-weeks. By 4-weeks post intervention, only 11% of women were still considering the lumpectomy vs. mastectomy choice and six percent were considering lymph node sampling choices, while one in three were still considering their chemotherapy options and more than one in four were considering Tamoxifen. In fact, chemotherapy choices were the most frequently cited and most frequently reported as the most important decision through the 2-month post-intervention point while Tamoxifen was the second most frequently cited treatment choice.

Similar to treatment decisions, the number of women indicating that they were considering non-treatment decisions decreased from 80% at 2 weeks post-intervention to 52% at 2 months (Table 7). There were no significant differences across the intervention groups in number of nontreatment decisions. While nontreatment decisions were less frequently cited at the 2-week post-intervention point (on average, 2.3 decisions, sd. 1.7), by the 2-month point there were as common as treatment decisions: on average, all women in the study were considering 1.0 nontreatment decisions (sd. 1.3) similar to 1.2 (sd 1.7) treatment decisions under consideration at 2-months. For the 52% of women considering any nontreatment decisions at 2 months, they were considering an average of 2.0 decisions (s.d 1.1) each, again similar to the 2.4 treatment decisions under consideration by the 52% who were considering any treatment choices.

The type of nontreatment decisions under consideration changed over time (Table 8). In the early stages, over half of the women were most frequently considering decisions such as who or what to tell family, friends, or coworkers about their condition. In fact, this was cited as the most important nontreatment decision they considered in the first 2 weeks of the intervention. During this same time period, almost four out of ten women were considering whether to go to a support group and one in three were thinking about who they wanted to be around. These decisions overtook who/what to tell as the most frequently cited nontreatment choices over the next two months.

Women in the study were also asked some questions about their most important decisions as reported in the 2-week post-intervention survey at the surveys conducted four months post-intervention (near the end of the intervention) and nine months post-intervention (several months after the end of the intervention). One of these questions concerned whether, knowing what they know now, they would still the same decision today. Responses to this compliance with decision question are reported in Table 9. At four months post-intervention, 87% of the women reported agreement or strong agreement with the statement "Knowing what I know now, I would still make the same decision today." By nine months post-intervention, this percentage decreased just slightly to 84%.

Items addressing subjects' satisfaction with their decisions were drawn from three existing scales: the Decision Attitude Scale also referred to as the PDS scale (Sainfort and Booske, 2000), the Decision Conflict Scale (O'Connor, 1995), and The Satisfaction with Decision Scale (Holmes-Rovner et al, 1996). After subjects were asked to indicate which treatment decisions they had been considering over the past two weeks, they were then asked to indicate which of these decisions was the most important to them. Then, thinking about this most important decision, they were asked to indicate their level of agreement or disagreement with a series of statements using a 5-point Likert scale (strongly disagree, disagree, neither agree or disagree, agree, strongly agree). A similar approach was used for addressing non-treatment decisions and satisfaction with these decisions with some minor modifications made to the statements for inquiring about satisfaction with non-treatment decisions. Table 10 provides a list of the items as they were used to address treatment and non-treatment decision satisfaction, along with the respective sources for each of these items. It is important to note that these items do not universally apply to all women in the study: the first set of items apply only to *women who have considered a decision in the past 2 weeks* while the second set apply only to the subset of these women *who have actually made a decision in the past 2 weeks*. Consequently, the number of women who responded to these items decreases over the course of the study as they found themselves facing fewer decisions. The entire set of questions was included in the first four surveys but to keep respondent burden to a reasonable level, only the last subset of five items were included in the 4-month and 9-month post intervention surveys.

Tables 11 and 12 provide descriptive statistics for the decision satisfaction items. In general, for all but three items, higher scores indicate higher levels of satisfaction with respect to that particular item. However, three items in these tables are italicized since they represent negatively framed questions. The scores reported represent actual responses, i.e., these scores have not been reversed and so a lower score is indicative of more disagreement with the statement and thus more positive decision satisfaction. The level of agreement with the statements was generally very high with only slight variation, with mean responses ranging from 3.6 to 4.2 (on a 5-point scale) for the positively framed items at two weeks post-intervention.

D.6. Hypothesis C: There will be a significant difference in patients' desire to participate in their treatment decisions among the technologies.

Table 13 presents a comparison of patients' desire to participate in decision making by intervention group at 2, 4, and 6 weeks post-intervention and at 2 months post-intervention. Using a standard Chi-square test, we found no significant difference in desire to participate among the intervention groups whether tested for CHESS versus Internet versus Control, CHESS versus Internet, CHESS versus Control, or Internet versus Control at any of the four points in time. Nor was there a significant effect observed for CHESS or Internet when covariates (age, race, insurance status, level of education, living alone, stage of cancer, time between diagnosis and intervention dates, or Karnofsky score) were included in logistic regression modeling for each of the preferred decision making styles (prefer to make own decision, prefer shared decision making, prefer doctor to make decision).

While no significant differences were found in patients' desire to participate in their treatment decisions among the technologies, there were some significant differences identified in subjects' propensity to change their preferred decision making style over the first 2 months with the intervention (Table 14). Comparing CHESS and Internet subjects, subjects assigned to these two technologies showed no significant differences in their tendency to change their preferred decision making style between the four survey points. However, CHESS subjects were less likely than Control subjects to change their preferred decision making style between 2 and 4 weeks ($p=.01$) and between 6 weeks and 2 months ($p=.04$) and Internet subjects were less likely than Control subjects to change their preferred decision making style between 4 and 6 weeks ($p=.03$). Over the course of the entire first two months with the intervention, CHESS subjects were significantly less likely to change their preferred decision making styles than subjects in the Control group ($p=.005$). Over the course of the 2 months, there were no significant differences between CHESS and Internet subjects or between Internet and Control subject in terms of their tendency to change their preferred decision making style. Where there were significant differences between subjects' tendency to change their preferred style, there was no significant difference in the direction of this tendency, i.e., some subjects changed toward a greater preference toward making their own decisions while others changed toward preferring having their doctor make decisions.

These findings continued when the study covariates were included in a logistic regression model: (Tables 15-19): between 2 weeks and 4 weeks post-intervention, compared to being in one of the other groups, membership in the CHESS group decreased the odds of changing preferred decision making style (Table 16); between 4 weeks and 6 weeks, women in the Internet group were more likely to change their preferred decision making style (Table 17); and between 6 weeks and 2 months, there were no significant differences between the intervention groups (Table 18). Over the course of the first two months of the intervention, women in the CHESS group were less likely to record any changes in their preferred decision making style (Table 19).

D.7. Hypothesis D: There will be a significant difference in satisfaction with treatment decisions among the technologies.

Examining the satisfaction with treatment decisions among the different intervention groups is the most complex aspect of the hypothesis testing for decision making due to the number of treatment decisions which women who are diagnosed with breast cancer face. To maximize

our ability to capture any impact of the technologies on treatment decisions, women in the study were asked to complete "decision making" surveys every two weeks for the first two months of the intervention. The purpose of this part of the survey design was to try to capture levels of satisfaction with decision making as near as possible to the decision making process. To capture longer term satisfaction with decisions, women in the study were also asked an abbreviated set of questions about their satisfaction with their choices at four and nine months post-intervention. Consequently, depending on the specific decision satisfaction item there were potentially either four or six data points. As previously described, women were asked to respond to these questions about their satisfaction with the treatment choice they considered to be most important at each point. Thus, for each subject, the different data points may reflect the same or different treatment choices.^{iv}

Since there is no one universally accepted approach to measuring decision satisfaction, we drew upon items developed by multiple researchers. However, we did not necessarily use entire scales since not all the items were always relevant. Furthermore, there was a need to avoid imposing too great a response burden on the women in the study. So, a total of fourteen items were selected from existing scales and two additional items were developed to capture the concept of satisfaction with decisions. To develop a new satisfaction with decision scale, we conducted a series of factor analyses of the 16 items at each point in time. The results of these factor analyses are provided in Table 20. Using a criteria requiring an eigenvalue of at least 1, two clear factors appeared to emerge from the 16 decision satisfaction items: the first factor seems to represent the subjects' satisfaction with the information that they have for making a decision and the second factor represents their satisfaction with their actual choice. There is a potential third factor that seems to reflect some indication of their level of comfort with their decision making (it was difficult to make a choice, consulting someone else would be helpful, I need more advice and information). One item, "It's clear what choice is best for me" did not clearly load on any of these factors however, four weeks, there was a fourth factor that was comprised of this item and an item from the third factor, "It is difficult to make a choice." Because it was not clear whether these last four items comprised one or two factors, we decided to keep these items separate from any factors.

Consequently, subsequent analysis involving testing the hypotheses was conducted using the two main decision satisfaction factors (satisfaction with information and satisfaction with choice) and with these four individual items resulting in six tests for each of the 2 week, 4 week, 6 week, and 2 month post-interventions. Since only the decision satisfaction items collected at 4 months and 9 months addressed satisfaction with choice items, there was just one test for each of these time periods. As with the other analyses of decision making, hypothesis testing for decision satisfaction involved first a bivariate comparisons of means for the three intervention groups (Table 21): for the two main factors, satisfaction with information and satisfaction with choice, the means were very similar across the groups for both factors and no statistically significant differences were identified across the three groups or in pairwise comparisons.

With respect to the four individual decision satisfaction items, there was only one statistically significant differences across the three groups (Tables 22-25). At 2 weeks post-intervention, CHESS subjects were less likely than Internet subjects ($F=5.16$, $p=.03$) and Control subjects ($F=6.49$, $p=.01$) to agree with the statement "It is clear what choice is best for me" Perhaps this suggests that those in the CHESS group already had experienced a greater recognition of the complexity of their options. In a pairwise comparison (i.e., the difference was not found

^{iv} Only 15 percent of the subjects reported on the same treatment decision in each survey they returned.

in a comparison of the three groups together) at 2 weeks post-intervention, women in the CHESS group were less likely to agree with the statement "Consulting someone else would have been useful in making this decision" than those in the Control group ($F=4.29$, $p=.04$). In a pairwise comparison at 2 months post-intervention, there was a difference between subjects in the Internet and Control groups regarding the need for more advice and information: Internet subjects were less likely to agree with the statement "I need more advice and information about my options" ($F=4.24$, $p=.04$).

Overall, we found little evidence to support the hypothesis that there was a difference in satisfaction with treatment decisions across the three groups. Incorporating the study covariates in multivariate modeling did not lead to identification of any additional significant findings. The results show that overall, all the women in the study were relatively satisfied with their decision making regardless of the form of decision support they received. As noted earlier in the report, in order to provide support for decisions following a diagnosis of breast cancer, interventions must be implemented as soon as possible. In this study, the number of women finding themselves in the situation of having decisions to make dropped off rapidly in the weeks following diagnosis. With such small numbers of women making decisions later in the intervention, only very large differences in decision satisfaction would be identified as statistically significant. Furthermore, this research has shown that the existing decision satisfaction scales do not possess a high level of discriminatory power, at least for decisions involving breast cancer treatment. There was a high level of agreement with the statements, particularly those with a positive frame. Only the questions with a negative frame exhibited significant levels of disagreement. This does suggest that at least some subjects were not applying social desirability in their responses.

Finally, it is important to stress that the failure to identify statistically significant differences in levels of satisfaction with *decision* support does not necessarily mean that the technologies do not provide other kinds of support that maybe equally as important if not more important to women faced with a diagnosis of breast cancer.

D.8. Hypothesis E: There will be a significant difference in compliance with decision among the technologies.

As described earlier in the report, compliance with decision was measured by a question on the four month and nine month surveys that addressed whether women would still make the same decision. Table 26 provides the percent of subjects in each of the intervention groups who indicated that they strongly disagreed, disagreed, neither agreed or disagreed, agreed, or strongly agreed with the statement "Knowing what I know now, I would still make the same decision today." Overall, there was a high level of agreement with the statement that increased from four months to nine months for subjects within each of the three groups. Using standard bivariate analytic tests (Chi-square and ANOVA F-test), there were no significant differences between compliance with decision for subjects in the three groups nor were any significant differences found when covariates were introduced. This was true whether the dependent variable was treated as a linear variable or a dichotomous variable (agree/strongly agree vs. all others or strongly agree vs. all others).

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- ⁱ That is, no comparisons reached $p < .05$ when comparing all three groups on dichotomous measures or reducing education and income to three categories. For four variables where one group seemed to differ from the other two, we did collapse groups and performed the two-column comparisons, but none of these tests survived correction for post-hoc comparisons – that the smallest p-value be smaller than $.05/4$ or $.0125$.
- ⁱⁱ In fact, when the two intervention groups were each compared to the control group, the only significant difference was that the CHESS group had greater functional well-being ($B = .10$, $d.f. = 10, 289$, $p = .042$).

Table 1
Demographic Characteristics of Subjects
with Internet, CHESS, Audio+Book groups (Number and Percent)

Variables	Internet (n=102)	CHESS (n=110)	Audio+Book (n=95)
Race			
Caucasian	76(74.5%)	86(78.2%)	78(82.1%)
Age			
Median	51.0	50.0	51.0
<65	85(83.3%)	99(90.0%)	79(83.2%)
Menopause status			
Pre-Menopause	36(36.4%)	47(44.3%)	33(36.3%)
Peri-Menopause	14(14.1%)	16(15.1%)	11(12.1%)
Post-Menopause	49(49.5%)	43(40.6%)	47(51.6%)
Interval since diagnosis			
Median	38.0	32.0	25.0
0<=Interval<62	79(77.5%)	90(81.8%)	83(87.4%)
Stage			
Early stage (stage 0, 1,2)	89(87.3%)	99(90.0%)	86(90.5%)
Insurance			
Public insurance (Medicaid or no insurance)	11(10.8%)	8(7.3%)	3(3.2%)
Live with someone else			
Yes	83(81.4%)	85(77.3%)	79(83.2%)
Household Income			
\$<=19,999	24 (25.2%)	13(12.6%)	12(13.3%)
20,000<=\$<=39,999	21(22.1%)	24(23.3%)	21(23.3%)
40,000<=\$<=59,999	16(16.8%)	21(20.4%)	18(20.0%)
60,000<=\$	34(35.8%)	45(43.7%)	39(43.3%)
Education			
Less than H.S. diploma	7(7.1%)	8(7.3%)	2(2.2%)
High school diploma	26(26.3%)	11(10.1%)	18(18.9%)
Some college courses	27(27.3%)	39(35.8%)	41(43.2%)
Bachelor's degree	21(21.2%)	26(23.9%)	19(20.0%)
Graduate degree	18(18.2%)	25(22.9%)	15(15.8%)

Table 1 Continued

**Demographic Characteristics of Subjects
with Internet, CHESS, Audio+Book groups (Number and Percent)**

Variables	Internet (n=102)	CHESS (n=110)	Audio+Book (n=95)
Karnofsky			
Feeling normal	84(82.4%)	97(88.2%)	71(74.7%)
Performing normal activities	15(14.7%)	12(10.9%)	23(24.2%)
Unable to carry on usual activities...	3(2.9%)	1(0.9%)	1(1.1%)
Disabled - requiring special care	0(0.0%)	0(0.0%)	0(0.0%)
Very sick, hospitalized, or in bed all of the time	0(0.0%)	0(0.0%)	0(0.0%)

Table 2**Regressions Results Comparing
CHESS vs. Internet Groups Only**

	Full Sample			W/in 2 mo. from diagnosis	
Dependent Variable	Beta	P		Beta	P
Social Support	.05	.16		.12	.04*
Health Self-efficacy	.06	.16		.11	.04*
Functional Well-being	.07	.13		.14	.01*
Emotional Well-being	.01	.41		.04	.26
Concerns	-.02	.35		.02	.37
Perceived Knowledge	.01	.42		.09	.10
N =	205			165	

Table 3

Preferred Decision Making Style

Preferred Decision Making Style	2 weeks post-intervention	4 weeks post-intervention	6 weeks post-intervention	2 months post-intervention
Prefer to make decision myself (with or without considering doctor's opinion)	41.1%	36.8%	36.4%	40.3%
Share responsibility for decision making with doctor	40.3%	45.5%	43.9%	43.1%
Prefer doctor makes decisions (with or without considering my opinion)	14.2%	10.3%	11.5%	11.5%
No response	4.3%	7.5%	8.3%	5.1%
Total	100.0%	100.0%	100.0%	100.0%

Table 4
Changes in Preferred Decision Making Style

	Between 2 weeks and 4 weeks post- intervention	Between 4 weeks and 6 weeks post- intervention	Between 6 weeks and 2 months post-intervention
Changed preferred decision making style			
Changed more toward making own decisions	30.8%	17.0%	28.1%
Changed more toward doctor making decisions	48.8%	54.9%	50.2%
	51.2%	45.1%	49.8%
No change in preferred decision making style	69.2%	83.0%	71.9%
Total	100.0%	100.0%	100.0%

Table 5
Number of Treatment Choices Under Consideration

Intervention	2 weeks post-intervention			4 weeks post-intervention			6 weeks post-intervention			2 months post-intervention		
	Mean number of treatment decisions for all subjects (sd)	Percent of subjects considering treatment choice at least one	Mean number of treatment decisions for subjects considering treatment choice	Mean number of treatment decisions for all subjects (sd)	Percent of subjects considering treatment choice at least one	Mean number of treatment decisions for subjects considering treatment choice	Mean number of treatment decisions for all subjects (sd)	Percent of subjects considering treatment choice at least one	Mean number of treatment decisions for subjects considering treatment choice	Mean number of treatment decisions for all subjects (sd)	Percent of subjects considering treatment choice at least one	Mean number of treatment decisions for subjects considering treatment choice
CHES	3.2 (2.5)	85.2%	3.9 (2.2)	1.9 (2.0)	69.8%	2.8 (1.8)	1.4 (1.9)	57.6%	2.5 (1.9)	1.3 (1.7)	52.4%	2.4 (1.6)
Internet	2.9 (2.4)	77.5%	3.9 (2.8)	1.5 (1.8)	56.4%	2.7 (1.54)	1.0 (1.4)	48.7%	2.1 (1.3)	1.0 (1.7)	48.7%	2.1 (1.9)
Control	<u>4.5 (3.3)</u>	<u>91.9%</u>	4.9 (3.0)	<u>2.1 (2.3)</u>	<u>67.5%</u>	<u>3.1 (2.1)</u>	<u>1.1 (1.4)</u>	<u>51.9%</u>	<u>2.2 (1.3)</u>	<u>1.1 (1.7)</u>	<u>53.0%</u>	<u>2.6 (1.5)</u>
Total	3.5 (2.9)	84.6%	4.2 (2.7)	1.9 (2.0)	64.8%	2.9 (1.8)	1.2 (1.6)	52.9%	2.3 (1.5)	1.2 (1.7)	51.8%	2.4 (1.6)
	F=5.67 (.00)		F=3.37 (.04)	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.

Table 6
Type of Treatment Choices Under Consideration

Treatment choices	2 weeks post-intervention		4 weeks post-intervention		6 weeks post-intervention		2 months post-intervention	
	Percent considering treatment choice	Percent citing treatment choice as their most important decision	Percent considering treatment choice	Percent citing treatment choice as their most important decision	Percent considering treatment choice	Percent citing treatment choice as their most important decision	Percent considering treatment choice	Percent citing treatment choice as their most important decision
Chemotherapy (whether to have/type/ length)	47%	25%	34%	23%	26%	18%	26%	15%
Lumpectomy versus mastectomy	34%	21%	11%	5%	4%	4%	5%	5%
Tamoxifen	41%	8%	27%	8%	19%	8%	23%	9%
Breast reconstruction	24%	8%	11%	4%	10%	4%	8%	3%
Radiation (what to radiate, e.g., axillary or underarm lymph nodes)	18%	3%	10%	6%	7%	5%	6%	4%
Lymph node	29%	4%	6%	0%	3%	1%	3%	0%
Clinical trial participation	19%	3%	11%	4%	5%	1%	5%	1%
Alternative treatment	11%	2%	8%	2%	5%	2%	7%	3%
Stopping treatment	3%	1%	2%	1%	3%	2%	4%	4%
Fine needle biopsy	10%	0%	3%	1%	1%	0%	2%	0%
Oophorectomy (ovary removal)	5%	1%	2%	1%	3%	0%	3%	1%
Immunotherapy	4%	1%	1%	0%	1%	0%	1%	0%
Bone marrow transplant	3%	0%	4%	0%	1%	0%	0%	0%
Other treatment decisions	7%	4%	8%	5%	5%	4%	7%	4%
Did not indicate most important decision	--	5%	--	6%	--	3%	--	2%
No treatment choices being considered	15%	15%	34%	34%	47%	47%	48%	48%
		100%		100%		100%		100%

Table 7
Number of Other (Non-Treatment) Choices Under Consideration

Intervention	2 weeks post-intervention			4 weeks post-intervention			6 weeks post-intervention			2 months post-intervention		
	Mean number of decisions for all subjects (sd)	Percent of subjects considering at least one decision	Mean number of decisions for subjects considering at least one decision	Mean number of decisions for all subjects (sd)	Percent of subjects considering at least one decision	Mean number of decisions for subjects considering at least one decision	Mean number of decisions for all subjects (sd)	Percent of subjects considering at least one decision	Mean number of decisions for subjects considering at least one decision	Mean number of decisions for all subjects (sd)	Percent of subjects considering at least one decision	Mean number of decisions for subjects considering at least one decision
CHES	2.3 (1.7)	79.5%	2.8 (1.4)	1.5 (1.4)	65.1%	2.3 (1.0)	1.3 (1.4)	62.4%	2.2 (1.2)	1.1 (1.4)	52.2%	2.1 (1.3)
Internet	2.3 (1.9)	75.0%	3.0 (1.6)	1.7 (1.7)	66.7%	2.5 (1.5)	1.2 (1.5)	59.2%	2.1 (1.3)	1.2 (1.4)	55.0%	2.1 (1.2)
Control	2.3 (1.6)	84.8%	2.7 (1.4)	1.4 (1.4)	65.0%	2.2 (1.2)	1.0 (1.1)	60.5%	1.7 (0.9)	0.9 (1.1)	49.4%	1.8 (0.9)
Total	2.3 (1.7)	79.8%	2.8 (1.5)	1.5 (1.5)	65.6%	2.3 (1.3)	1.2 (1.3)	60.7%	2.0 (1.1)	1.0 (1.3)	52.2%	2.0 (1.1)
	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.	n.s.		n.s.

Table 8
Other Decisions (Non-Treatment) Under Consideration

Treatment choices	2 weeks post-intervention		4 weeks post-intervention		6 weeks post-intervention		2 months post-intervention	
	Percent considering decision	Percent citing decision as their most important	Percent considering decision	Percent citing decision as their most important	Percent considering decision	Percent citing decision as their most important	Percent considering decision	Percent citing decision as their most important
Who/what to tell family/friends/coworkers	54%	25%	26%	11%	19%	9%	17%	7%
Whether to quit work/go back to work	28%	12%	19%	9%	12%	7%	15%	8%
Whether to seek a second opinion	23%	10%	16%	7%	10%	4%	9%	5%
Whether to change doctor	15%	7%	9%	6%	4%	4%	4%	2%
Whether to go to a support group	38%	5%	29%	7%	28%	10%	25%	9%
Who to be around	30%	4%	29%	9%	23%	10%	19%	8%
Whether to quit smoking	11%	2%	8%	3%	5%	3%	6%	4%
End of life decisions	10%	2%	4%	2%	3%	2%	2%	1%
Whether to leave partner	4%	2%	4%	2%	4%	3%	4%	2%
Other nontreatment decisions	7%	4%	4%	3%	6%	4%	3%	3%
Did not pick most important	--	4%	--	4%	--	2%	--	2%
No nontreatment decisions	23%	23%	38%	38%	42%	42%	48%	48%
Total		100%		100%		100%		100%

Table 9
Compliance with Earlier Decisions

Knowing what I know now, I would still make the same decision today	4 months post-intervention		9 months post-intervention	
Strongly disagree		1.7%		2.3%
Disagree		3.4%		5.9%
Neither agree or disagree		8.2%		7.7%
Agree		43.1%		36.2%
Strongly Agree		<u>43.5%</u>		<u>48.0%</u>
Total		100.0%		100.0%

Table 10
Decision Satisfaction Items

Treatment Decisions	Non-Treatment Decisions	Source
<i>For all women who have been considering at least one decision over the past 2 weeks:</i>		
It is difficult to make a choice.	It is difficult for me to make a choice.	Sainfort and Booske
It's clear what choice is best for me.	It's clear what choice is best for me.	O'Connor
I'm aware of choices I have in making this decision.	I'm aware of the choices I have in making this decision.	O'Connor
I know the relative benefits of my options for this decision.	I feel I know the relative benefits & risks of my options for this decision.	O'Connor
I know the relative risks and side effects of my options for this decision.		O'Connor
The information I have to make this decision is easy to understand.		Sainfort and Booske
I have no problem using the information I have in making this decision.		Sainfort and Booske
Consulting someone else would have been useful in making this decision.	Consulting someone else would be useful in making this decision.	Sainfort and Booske
I am satisfied that I am adequately informed about the issues important to my decision.	I am satisfied that I am adequately informed about the issues important to my decision.	Holmes-Rovner et al
I need more advice and information about my options.	I need more advice and information about my options.	O'Connor
I have access to information on all my options.	I have access to information on all my options.	
	I have the right amount of support from others in making this decision.	
<i>For women who have decided what to do for this decision:</i>		
My treatment choice is sound.	My decision is sound.	Sainfort and Booske
I am satisfied with my treatment choice.	I am satisfied with my decision.	Holmes-Rovner et al
		O'Connor
		Sainfort and Booske
My treatment choice is the right one for my situation.	My decision is the right one for my situation.	Sainfort and Booske
I am satisfied that my treatment choice was consistent with my personal values.	I am satisfied that my decision was consistent with my personal values.	Holmes-Rovner et al
I feel I have made an informed choice.	I feel I have made an informed choice.	O'Connor

Table 11
Summary Statistics of Treatment Decision Satisfaction Items

Decision Satisfaction Items	2 weeks post-intervention		4 weeks post-intervention		6 weeks post-intervention		2 months post-intervention		4 months post-intervention		9 months post-intervention	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
<i>It is difficult to make a choice.</i>	3.3	1.3	3.2	1.3	3.0	1.2	2.8	1.3				
<i>It's clear what choice is best for me.</i>	3.6	1.2	3.6	1.1	3.5	1.1	3.6	1.0				
<i>I'm aware of choices I have in making this decision.</i>	4.2	0.7	4.1	0.7	4.0	0.8	4.1	0.7				
<i>I know the relative benefits of my options for this decision.</i>	4.1	0.8	4.0	0.7	3.9	0.8	3.9	0.8				
<i>I know the relative risks and side effects of my options for this decision.</i>	4.0	0.8	3.9	0.8	3.9	0.8	3.9	0.9				
<i>The information I have to make this decision is easy to understand.</i>	3.7	1.0	3.6	0.9	3.7	0.9	3.7	0.8				
<i>I have no problem using the information I have in making this decision.</i>	3.8	0.9	3.7	1.0	3.7	0.9	3.8	0.8				
<i>Consulting someone else would have been useful in making this decision.</i>	3.2	1.2	3.2	1.1	3.2	1.0	3.3	1.1				
<i>I am satisfied that I am adequately informed about the issues important to my decision.</i>	3.8	1.0	3.8	0.9	3.8	0.9	3.7	1.0				
<i>I need more advice and information about my options.</i>	2.8	1.1	2.7	1.1	2.8	1.0	2.8	1.2				
<i>I have access to information on all my options.</i>	4.0	0.9	3.9	0.9	3.8	0.9	3.8	0.9				
<i>My treatment choice is sound.</i>	4.2	0.7	4.2	0.6	4.1	0.6	4.0	0.8	4.2	0.8	4.3	0.8
<i>I am satisfied with my treatment choice.</i>	4.1	0.7	4.1	0.6	4.1	0.7	4.0	0.7	4.2	0.8	4.2	0.9
<i>My treatment choice is the right one for my situation.</i>	4.1	0.7	4.2	0.6	4.2	0.5	4.1	0.6	4.3	0.8	4.3	0.8
<i>I am satisfied that my treatment choice was consistent with my personal values.</i>	4.1	0.7	4.1	0.7	4.1	0.6	4.0	0.7	4.3	0.8	4.2	0.8
<i>I feel I have made an informed choice.</i>	4.1	0.7	4.2	0.6	4.1	0.7	4.1	0.8	4.3	0.8	4.2	0.9

Table 12
Summary Statistics of Non-Treatment Decision Satisfaction Items

Decision Satisfaction Items	2 weeks post-intervention		4 weeks post-intervention		6 weeks post-intervention		2 months post-intervention	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
<i>It is difficult for me to make a choice.</i>	2.9	1.2	2.9	1.1	2.7	1.1	2.9	1.2
<i>It's clear what choice is best for me.</i>	3.6	1.0	3.5	1.0	3.6	0.9	3.4	1.1
<i>I'm aware of the choices I have in making this decision.</i>	4.0	0.7	4.0	0.7	4.0	0.7	3.9	0.7
<i>I feel I know the relative benefits & risks of my options for this decision.</i>	3.9	0.8	3.8	0.8	3.9	0.7	3.8	0.8
<i>Consulting someone else would be useful in making this decision.</i>	3.4	1.1	3.3	1.0	3.1	1.1	3.1	1.1
<i>I am satisfied that I am adequately informed about the issues important to my decision.</i>	3.7	1.0	3.8	0.9	3.7	0.9	3.8	0.9
<i>I need more advice and information about my options.</i>	2.8	1.1	2.8	1.1	2.6	1.0	2.7	1.1
<i>I have access to information on all my options.</i>	3.7	1.0	3.7	0.9	3.7	0.9	3.7	0.9
<i>I have the right amount of support from others in making this decision.</i>	4.0	0.9	3.8	1.0	3.9	0.9	3.8	0.9
<i>My decision is sound.</i>	4.0	0.8	4.0	0.7	4.0	0.8	3.8	0.9
<i>I am satisfied with my decision.</i>	4.1	0.8	4.0	0.7	4.0	0.7	4.0	0.8
<i>My decision is the right one for my situation.</i>	4.2	0.7	4.1	0.6	4.1	0.7	4.0	0.8
<i>I am satisfied that my decision was consistent with my personal values.</i>	4.2	0.7	4.1	0.7	4.0	0.7	4.0	0.8

Table 13
Preferred Decision Making Style by Intervention

Intervention	2 weeks post-intervention			4 weeks post-intervention			6 weeks post-intervention			2 months post-intervention		
	Prefer to make decision myself	Prefer to share responsibility for making decision with doctor	Prefer that doctor makes decision	Prefer to make decision myself	Prefer to share responsibility for making decision with doctor	Prefer that doctor makes decision	Prefer to make decision myself	Prefer to share responsibility for making decision with doctor	Prefer that doctor makes decision	Prefer to make decision myself	Prefer to share responsibility for making decision with doctor	Prefer that doctor makes decision
	Percent of subjects in each intervention group											
CHES	40.7	45.3	14.0	42.5	40.0	17.5	40.7	43.2	16.0	36.1	50.6	13.3
Internet	46.8	36.4	16.9	42.7	48.0	9.3	45.8	41.7	12.5	47.4	38.2	14.5
Control	41.8	44.3	13.9	34.2	59.5	6.3	32.9	58.2	8.9	44.4	46.9	8.6
All subjects	43.0	42.1	14.9	39.7	49.1	11.1	39.7	47.8	12.5	42.5	45.4	12.1
	n.s.			n.s.			n.s.			n.s.		

n.s. Chi-square not significant

Note: Excludes subjects that did not provide a response to this question.

Table 14
Change in Preferred Decision Making Style by Intervention

Intervention	Between 2 and 4 weeks post-intervention		Between 4 and 6 weeks post-intervention		Between 6 weeks and 2 months post-intervention		Anytime between 2 weeks and 2 months post-intervention	
	No change in preferred decision making style	Change in preferred decision making style	No change in preferred decision making style	Change in preferred decision making style	No change in preferred decision making style	Change in preferred decision making style	No change in preferred decision making style	Change in preferred decision making style
Percent of subjects in each intervention group								
CHES	77.8	22.2	85.6	14.4	77.8	22.2	60.0	40.0
Internet	68.8	31.3	75.0	25.0	73.8	26.3	51.3	48.8
Control	60.2	39.8	88.0	12.0	63.9	36.1	38.6	61.4
Total	69.2	30.8	83.0	17.0	71.9	28.1	50.2	49.8
	p=.04		p=.06		n.s.		p=.02	

n.s. Chi-square not significant.

Note: Excludes subjects that did not provide a response to this question.

Table 15
Direction of Change in Preferred Decision Making Style by Intervention

Intervention	Between 2 and 4 weeks post-intervention		Between 4 and 6 weeks post-intervention		Between 6 weeks and 2 months post-intervention	
	Changed more toward making own decisions	Changed more toward doctor making decisions	Changed more toward making own decisions	Changed more toward doctor making decisions	Changed more toward making own decisions	Changed more toward doctor making decisions
	Percent of subjects in each intervention group					
CHESS	50.0	50.0	53.8	46.2	50.0	50.0
Internet	48.0	52.0	50.0	50.0	52.4	47.6
Control	48.5	51.5	40.0	60.0	60.0	40.0
Total	48.7	51.3	48.8	51.2	54.9	45.1
	n.s.		n.s.		n.s.	

n.s. Chi-square not significant.

Note: Includes only subjects that indicated a change in preferred decision making style.

Table 16

Logistic regression of change in preferred decision making style (versus no change)
between 2 weeks and 4 weeks post-intervention

Independent variables	B	S.E.	Sig.	Odds Ratio			95.0% Confidence Interval for Odds Ratio	
				Ratio	Lower	Upper	Lower	Upper
Constant	-0.91	1.17	0.437	0.40				
Age	0.02	0.01	0.169	1.02	0.99	1.05		
Race			0.784					
African American compared to Caucasian	0.14	0.48	0.765	1.15	0.45	2.93		
Other compared to Caucasian	0.66	1.03	0.520	1.94	0.26	14.63		
Publicly insured compared to privately insured	0.90	0.69	0.192	2.47	0.64	9.58		
Living alone compared to living with others	-1.01	0.43	0.021	0.37	0.16	0.86		
Early stage compared to late stage	-0.27	0.47	0.572	0.77	0.30	1.94		
Days between diagnosis and intervention	-0.01	0.01	0.276	0.99	0.97	1.01		
Karnofsky scale	-0.16	0.36	0.660	0.85	0.42	1.74		
Highest level of education	0.06	0.13	0.621	1.07	0.83	1.38		
CHES subjects compared to non-CHES	-0.77	0.36	0.032	0.46	0.23	0.94		
INTERNET subjects compared to non-Internet	-0.36	0.36	0.307	0.70	0.35	1.40		

NOTE: Cox & Snell R-square=.06

Table 17

Logistic regression of change in preferred decision making style (versus no change)
between 4 weeks and 6 weeks post-intervention

Independent variables	B	S.E.	Sig.	Odds Ratio	95.0% Confidence Interval for Odds Ratio	
					Lower	Upper
Constant	-4.85	1.62	0.003	0.01		
Age	0.01	0.02	0.405	1.01	0.98	1.05
Race			0.725			
African American compared to Caucasian	0.23	0.58	0.690	1.26	0.40	3.95
Other compared to Caucasian	0.86	1.21	0.475	2.36	0.22	25.08
Publicly insured compared to privately insured	-0.53	0.85	0.531	0.59	0.11	3.09
Living alone compared to living with others	0.13	0.45	0.767	1.14	0.47	2.79
Early stage compared to late stage	1.34	0.82	0.102	3.81	0.77	18.98
Days between diagnosis and intervention	-0.01	0.01	0.328	0.99	0.96	1.01
Karnofsky scale	0.93	0.42	0.027	2.54	1.11	5.81
Highest level of education	-0.04	0.16	0.802	0.96	0.70	1.31
CHESS subjects compared to non-CHESS	0.50	0.48	0.300	1.65	0.64	4.23
INTERNET subjects compared to non-Internet	1.24	0.46	0.008	3.47	1.39	8.62

NOTE: Cox & Snell R-square=.06

Table 18
Logistic regression of change in preferred decision making style (versus no change)
between 6 weeks and 2 months post-intervention

Independent variables	B	S.E.	Sig.	Odds Ratio	95.0% Confidence Interval for Odds Ratio	
					Lower	Upper
Constant	-4.99	1.47	0.001	0.01		
Age	0.03	0.01	0.041	1.03	1.00	1.06
Race			0.840			
African American compared to Caucasian	0.23	0.49	0.636	1.26	0.48	3.32
Other compared to Caucasian	-6.28	17.86	0.725	0.00		
Publicly insured compared to privately insured	0.90	0.73	0.217	2.47	0.59	10.40
Living alone compared to living with others	-0.44	0.43	0.299	0.64	0.28	1.48
Early stage compared to late stage	2.11	0.81	0.009	8.28	1.70	40.29
Days between diagnosis and intervention	0.01	0.01	0.497	1.01	0.99	1.03
Karnofsky scale	0.81	0.37	0.031	2.25	1.08	4.68
Highest level of education	-0.07	0.14	0.626	0.94	0.71	1.22
CHESS subjects compared to non-CHESS	-0.70	0.38	0.066	0.50	0.24	1.05
INTERNET subjects compared to non-Internet	-0.53	0.39	0.170	0.59	0.28	1.26

NOTE: Cox & Snell R-square=.12

Table 19
Logistic regression of any change in preferred decision making style (versus no change)
between 2 weeks and 2 months post-intervention

Independent variables	B	S.E.	Sig.	Odds Ratio			95.0% Confidence Interval for Odds Ratio	
				Ratio	Lower	Upper	Lower	Upper
Constant	-2.27	1.14	0.004	0.10				
Age	0.03	0.01	0.02	1.03			1.01	1.06
Race			0.14					
African American compared to Caucasian	0.90	0.46	0.05	2.46			1.00	6.03
Other compared to Caucasian	0.01	1.04	0.99	1.01			0.13	7.86
Publicly insured compared to privately insured	1.08	0.71	0.13	2.95			0.73	11.91
Living alone compared to living with others	-0.87	0.38	0.02	0.42			0.20	0.88
Early stage compared to late stage	0.47	0.47	0.32	1.60			0.63	4.02
Days between diagnosis and intervention	-0.01	0.01	0.51	0.99			0.98	1.01
Karnofsky scale	0.48	0.36	0.19	1.62			0.79	3.29
Highest level of education	0.06	0.12	0.62	1.06			0.83	1.36
CHES subjects compared to non-CHES	-0.83	0.34	0.01	0.43			0.22	0.84
INTERNET subjects compared to non-Internet	-0.54	0.35	0.12	0.58			0.29	1.16

NOTE: Cox & Snell R-square=.11

Table 20
Results of Factor Analysis of Satisfaction with Treatment Decision Process Items

	2 weeks post-intervention			4 weeks post-intervention				6 weeks post-intervention			2 months post-intervention		
	Factor 1	Factor 2	Factor 3	Factor 1	Factor 2	Factor 3	Factor 4	Factor 1	Factor 2	Factor 3	Factor 1	Factor 2	Factor 3
I know the relative benefits of my options for this decision.	0.810			0.474	0.549			0.781			0.489	0.720	
I have no problem using the information I have in making this decision.	0.774				0.643	0.485		0.700				0.676	
I know the relative risks and side effects of my options for this decision.	0.759				0.668			0.853			0.541	0.648	
The information I have to make this decision is easy to understand.	0.751				0.566	0.557		0.730				0.786	
I'm aware of the choices I have in making this decision.	0.707			0.581	0.473			0.697			0.580	0.546	
I am satisfied that I am adequately informed about the issues important to my decision.	0.704			0.554	0.501			0.707	0.480		0.516	0.457	
I have access to information on all my options.	0.695				0.809			0.698				0.814	
It's clear what choice is best for me.	0.479		0.419			0.651		0.449	0.432		0.610	0.428	
I feel I have made an informed choice.		0.818		0.790	0.413			0.575	0.682		0.783		
My treatment choice is the right one for my situation.		0.882		0.854					0.840		0.882		
I am satisfied with my treatment choice.		0.879		0.895				0.473	0.780		0.867		
I am satisfied that my treatment choice was consistent with my personal values.		0.841		0.844					0.800		0.844		
My treatment choice is sound.		0.898		0.847					0.771		0.783		
It is difficult to make a choice.			0.736			-0.827				0.665			-0.694
Consulting someone else would have been useful in making this decision.			0.732				0.775			0.820			-0.791
I need more advice and information about my options.			0.614				0.816	-0.586					-0.722

Note: N for each factor analysis decreases with the time period as fewer subjects indicated that they had made treatment decisions.

Table 21
Comparison of Treatment Decision Satisfaction Means by Intervention

Intervention		2 weeks post-intervention		4 weeks post-intervention		6 weeks post-intervention		2 months post-intervention		4 months post-intervention		9 months post-intervention	
		Information	Choice	Information	Choice	Information	Choice	Information	Choice	Information	Choice	Information	Choice
CHESS	Mean	3.9	4.1	3.9	4.2	3.9	4.0	3.8	4.0	4.2	4.3		
	Std. Deviation	0.7	0.6	0.6	0.6	0.7	0.6	0.7	0.6	0.8	0.8		
	N	79	66	68	52	57	47	51	42	82	78		
Internet	Mean	3.9	4.1	3.9	4.2	3.9	4.2	3.9	4.1	4.2	4.2		
	Std. Deviation	0.8	0.7	0.6	0.5	0.6	0.4	0.6	0.6	0.8	0.8		
	N	65	54	54	47	40	29	45	32	73	71		
Control	Mean	4.0	4.2	3.7	4.1	3.8	4.2	3.8	4.1	4.4	4.3		
	Std. Deviation	0.6	0.6	0.8	0.7	0.8	0.6	0.7	0.8	0.6	0.8		
	N	75	68	61	49	50	44	48	40	76	72		
All Subjects	Mean	3.9	4.1	3.8	4.2	3.8	4.1	3.8	4.0	4.2	4.3		
	Std. Deviation	0.7	0.6	0.7	0.6	0.7	0.6	0.7	0.7	0.7	0.8		
	N	219	188	183	148	147	120	144	114	231	221		
		n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.		

n.s. No significant difference between means.

Table 22
Comparison of "It is difficult to make a choice" across intervention groups

		2 weeks post-intervention	4 weeks post-intervention	6 weeks post-intervention	2 months post-intervention
CHESS	Mean	2.6	3.2	3.1	2.9
	Std. Deviation	1.4	1.3	1.2	1.2
	N	78	67	55	49
Internet	Mean	2.9	3.2	3.3	2.8
	Std. Deviation	1.3	1.3	1.2	1.2
	N	65	52	39	45
Control	Mean	2.6	3.1	2.8	2.8
	Std. Deviation	1.2	1.3	1.2	1.4
	N	72	61	48	48
Total	Mean	2.7	3.2	3.0	2.8
	Std. Deviation	1.3	1.3	1.2	1.3
	N	215	180	142	142
		n.s.	n.s.	n.s.	n.s.

Note: This item was reversed so a higher score indicates more disagreement with the statement.

Table 23
Comparison of "It's clear what choice is best for me" across intervention groups

		2 weeks post-intervention	4 weeks post-intervention	6 weeks post-intervention	2 months post-intervention
CHESS	Mean	3.3	3.4	3.3	3.4
	Std. Deviation	1.3	1.2	1.0	1.1
	N	77	68	57	51
Internet	Mean	3.6	3.7	3.8	3.7
	Std. Deviation	1.2	1.0	0.9	0.9
	N	66	54	40	45
Control	Mean	3.8	3.7	3.6	3.7
	Std. Deviation	1.0	1.1	1.2	1.0
	N	75	61	49	48
Total	Mean	3.6	3.6	3.5	3.6
	Std. Deviation	1.2	1.1	1.1	1.0
	N	218	183	146	144
		F=3.24 (p=.04)			
			n.s.	n.s.	n.s.

Table 24
Comparison of "Consulting someone else would have been useful in making this decision"
across intervention groups

		2 weeks post-intervention	4 weeks post-intervention	6 weeks post-intervention	2 months post-intervention
CHESS	Mean	2.6	3.3	3.4	3.3
	Std. Deviation	1.2	1.0	1.1	1.1
	N	79	66	56	50
Internet	Mean	2.8	3.2	3.0	3.2
	Std. Deviation	1.2	1.2	1.0	1.1
	N	64	54	39	43
Control	Mean	3.0	3.0	3.0	3.4
	Std. Deviation	1.1	1.1	1.0	1.0
	N	75	61	49	48
Total	Mean	2.8	3.2	3.2	3.3
	Std. Deviation	1.2	1.1	1.0	1.1
	N	218	181	144	141
		n.s.	n.s.	n.s.	n.s.

Note: This item was reversed so a higher score indicates more disagreement with the statement.

Table 25
Comparison of "I need more advice and information" across intervention groups

		2 weeks post-intervention	4 weeks post-intervention	6 weeks post-intervention	2 months post-intervention
CHESS	Mean	3.1	2.7	2.7	2.8
	Std. Deviation	1.2	1.1	1.0	1.1
	N	78	68	57	50
Internet	Mean	3.2	2.5	2.7	2.5
	Std. Deviation	1.1	1.1	1.0	1.0
	N	64	53	39	43
Control	Mean	3.2	2.7	2.8	3.0
	Std. Deviation	1.1	1.0	1.0	1.3
	N	75	61	50	48
Total	Mean	3.2	2.7	2.8	2.8
	Std. Deviation	1.1	1.1	1.0	1.2
	N	217	182	146	141
		n.s.	n.s.	n.s.	n.s.

Note: This item was reversed so a higher score indicates more disagreement with the statement.

Table 26
Compliance with Decision by Intervention Group

Knowing what I know now, I would still make the same decision today.	4 months post-intervention				9 months post-intervention				
	Strongly Disagree	Neither		Strongly Agree	Strongly Disagree	Neither		Strongly Agree	
		Disagree	Agree or Disagree			Disagree	Agree or Disagree		
					Percent of subjects in each intervention group				
CHESS	2.4	3.6	7.2	42.2	44.6	2.6	6.4	33.3	51.3
Internet	2.7	4.1	6.8	47.9	38.4	1.4	9.9	32.4	45.1
Control	0.0	2.6	10.5	39.5	47.4	2.8	1.4	43.1	47.2
All subjects	1.7	3.4	8.2	43.1	43.5	2.3	5.9	36.2	48.0

Figure 1
Average Number of Logins per Participant

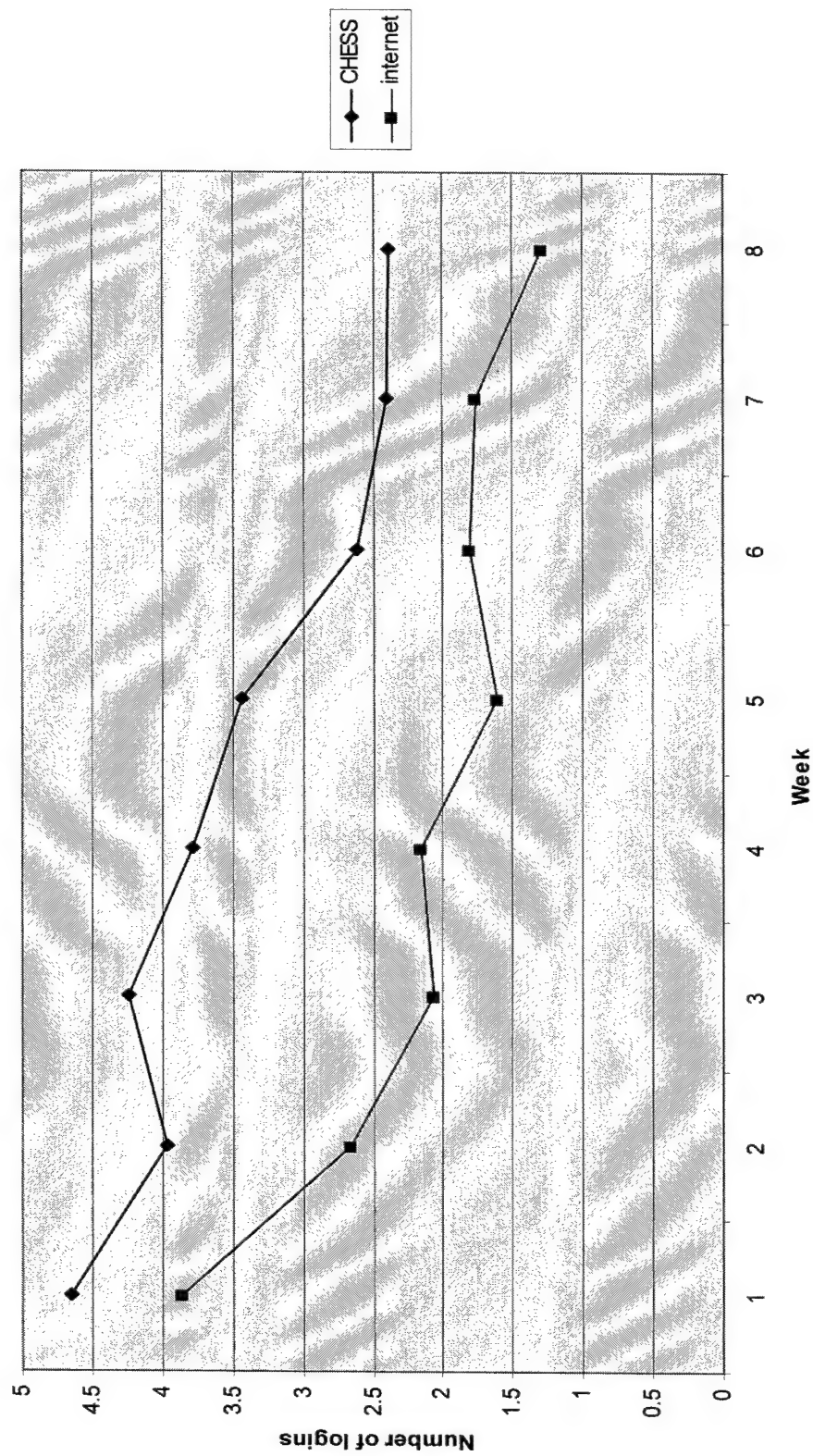


Figure 2
Total Time Spent Using the Computer per Subject

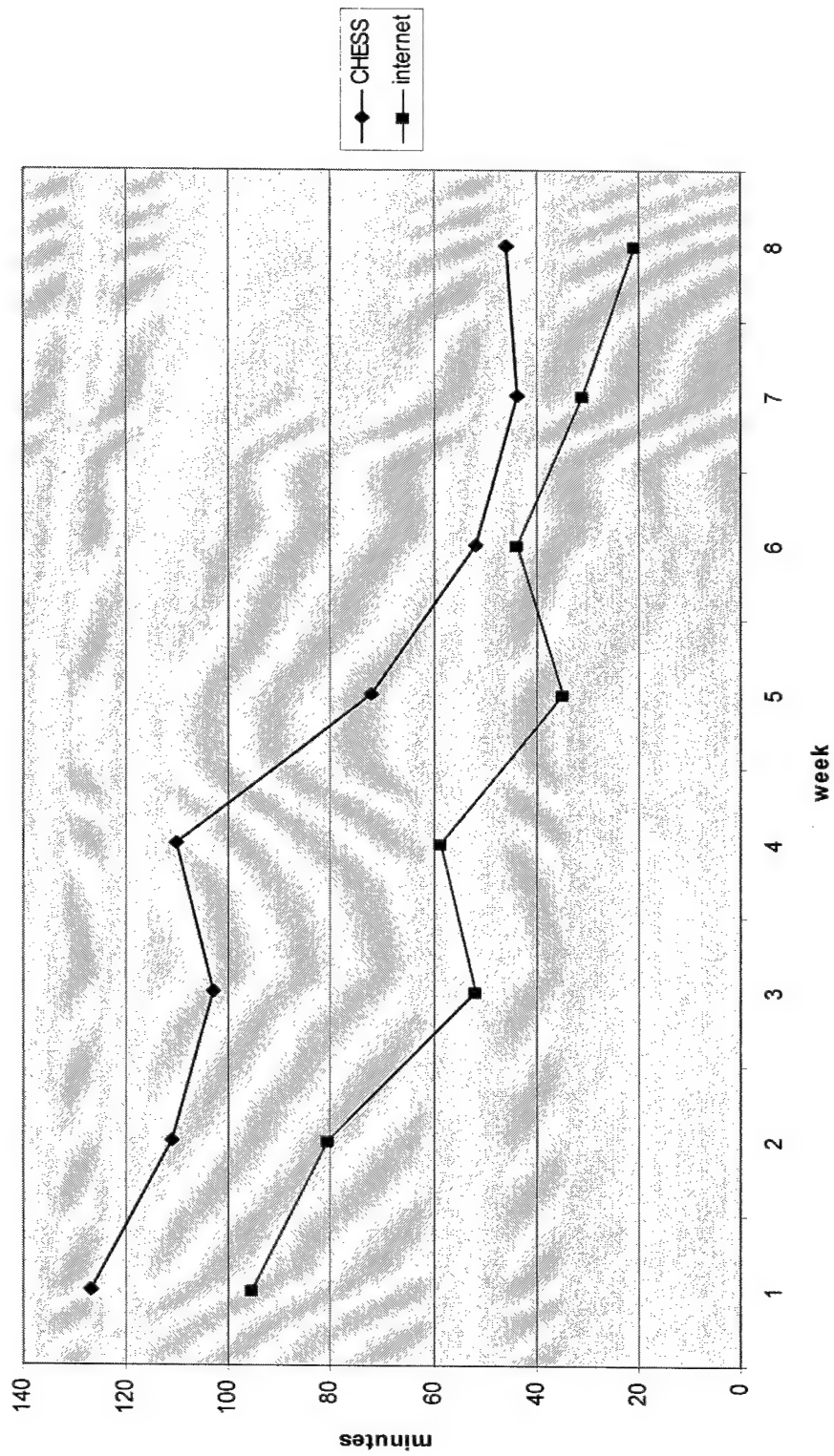


Figure 3
Cumulative Percent of Users

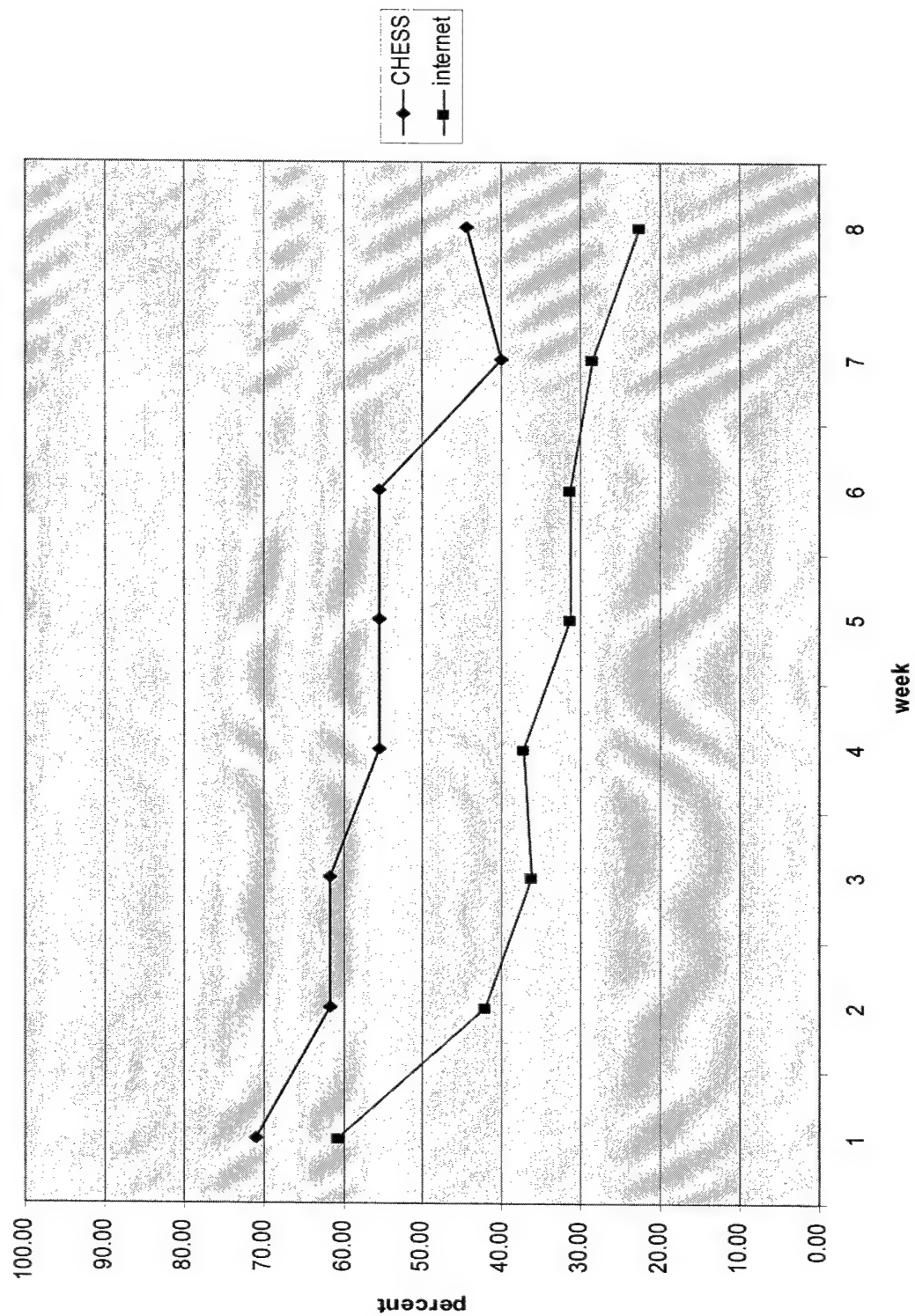


Figure 4
Time Spent per Logon

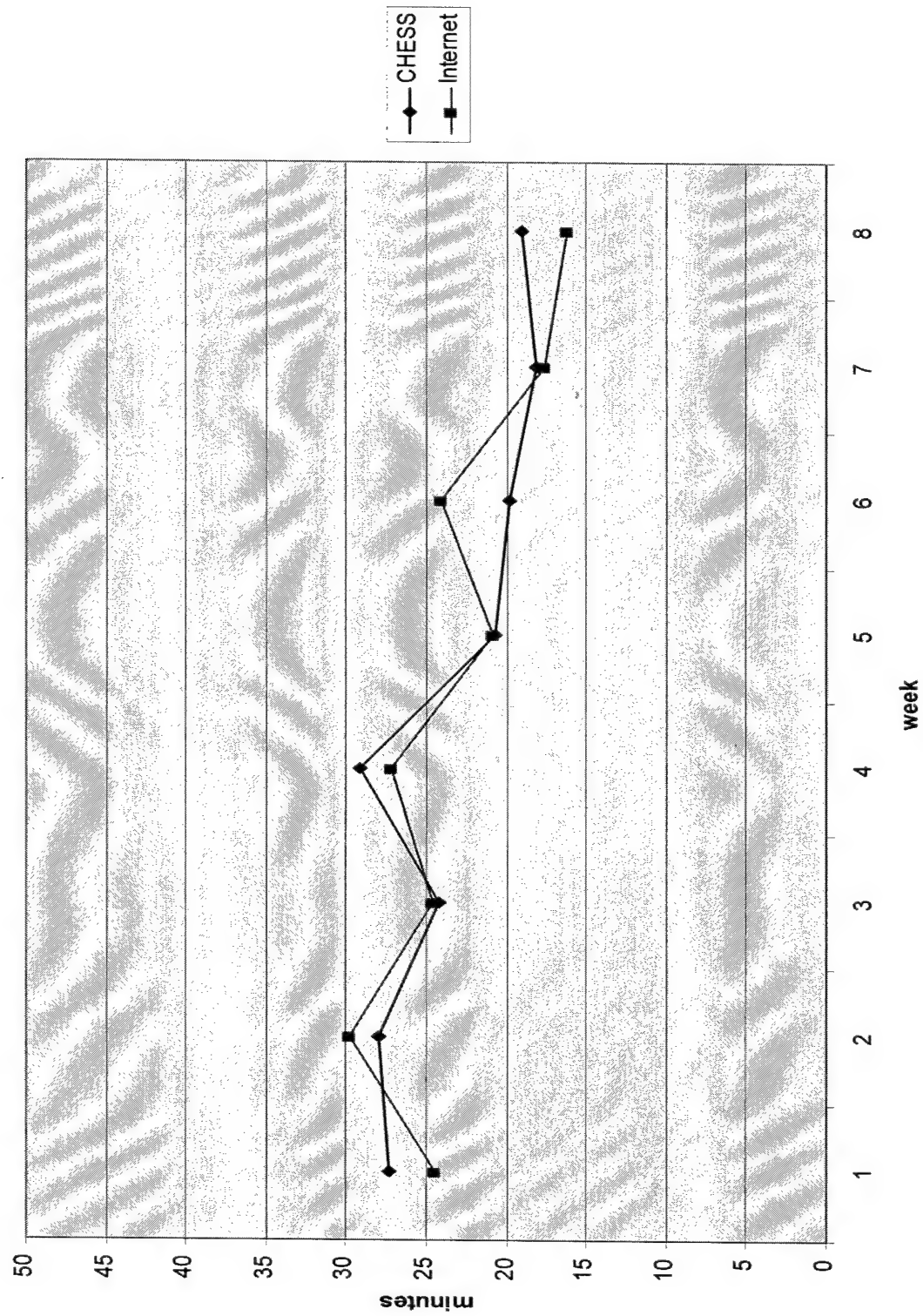


Figure 5
Time Spent in Non Health Related URLs

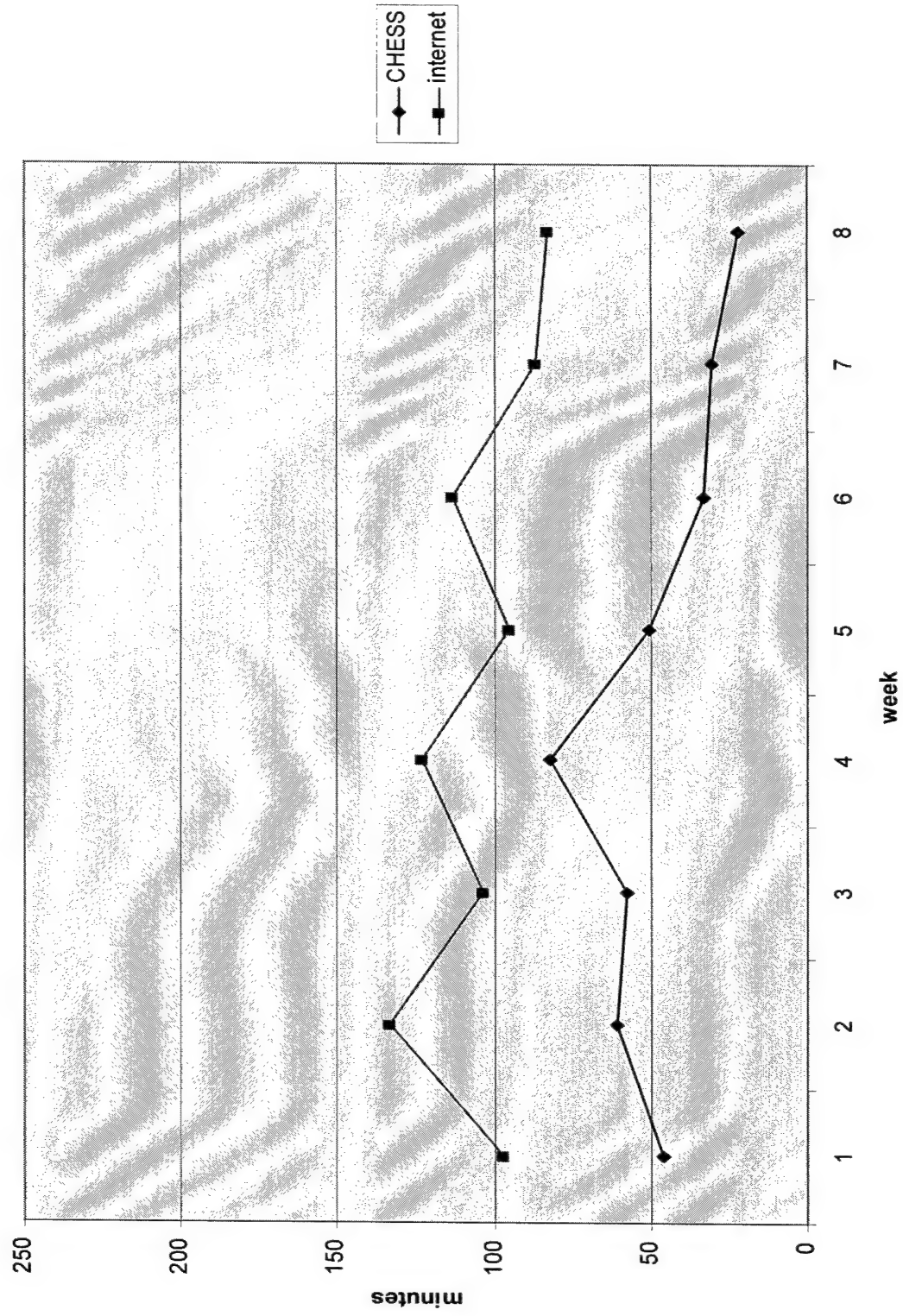


Figure 6
Time Spent in Health Related URLs

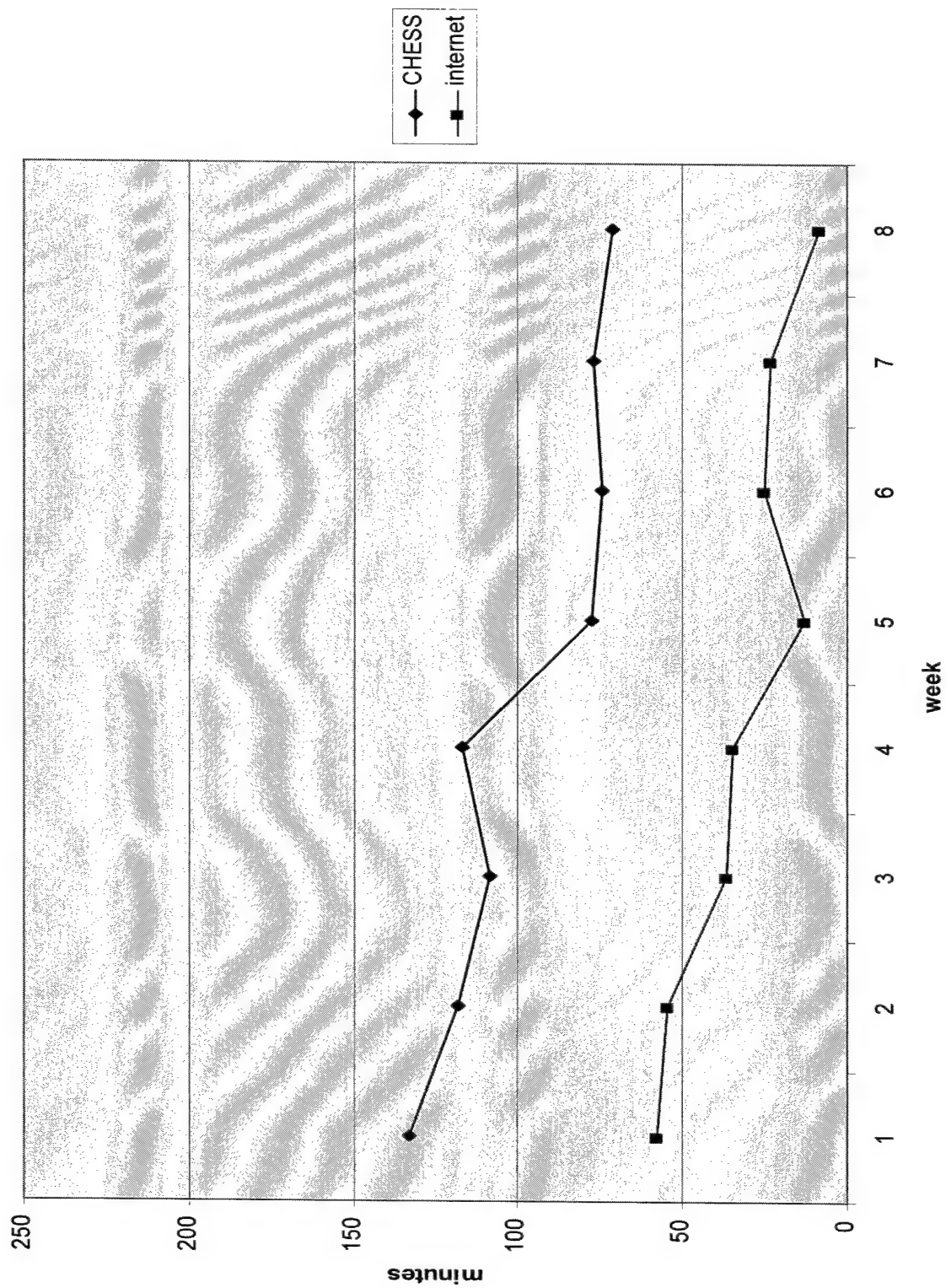


Figure 7
Time Spent in Health Related URLs Excluding CHES

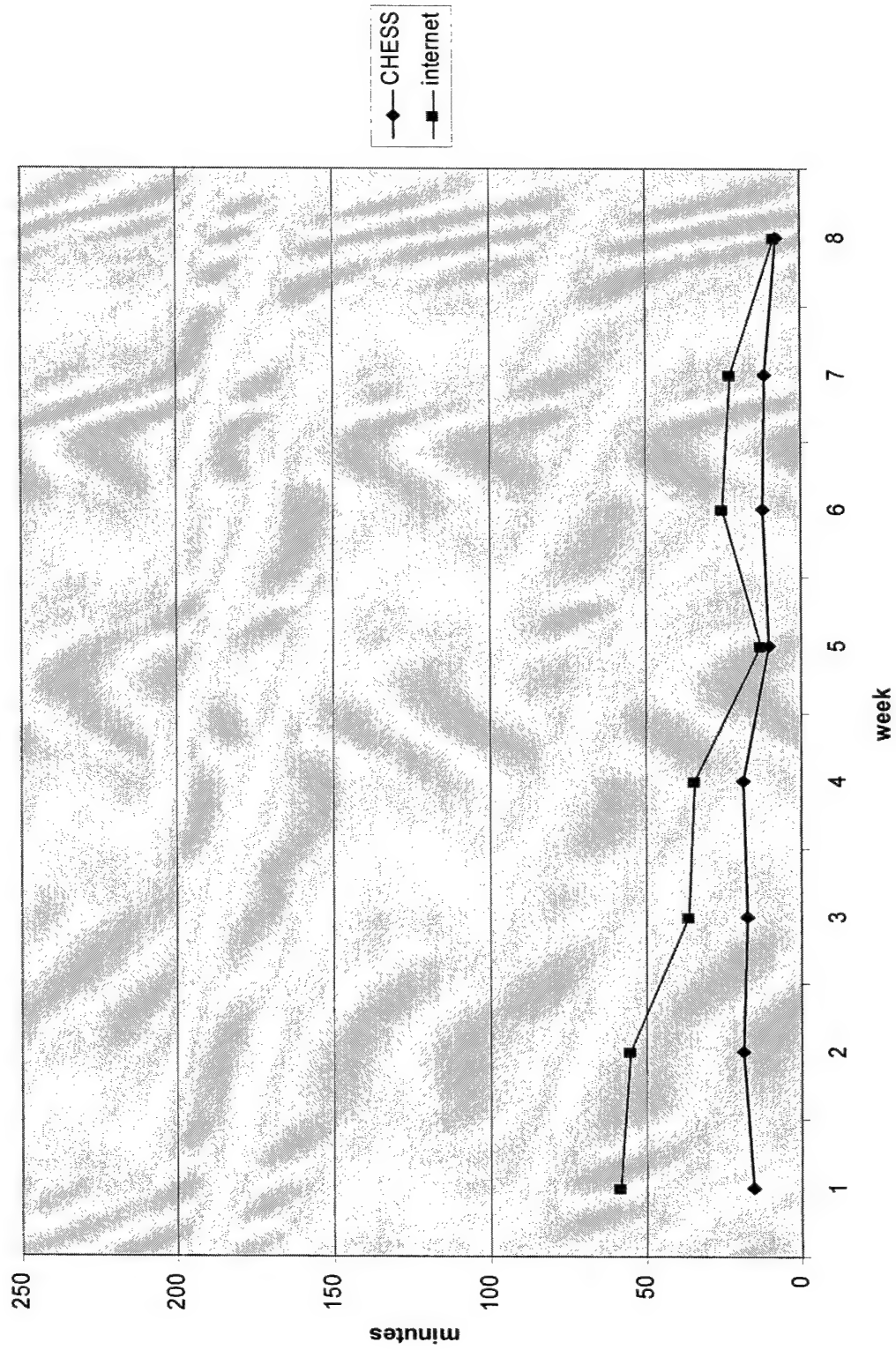
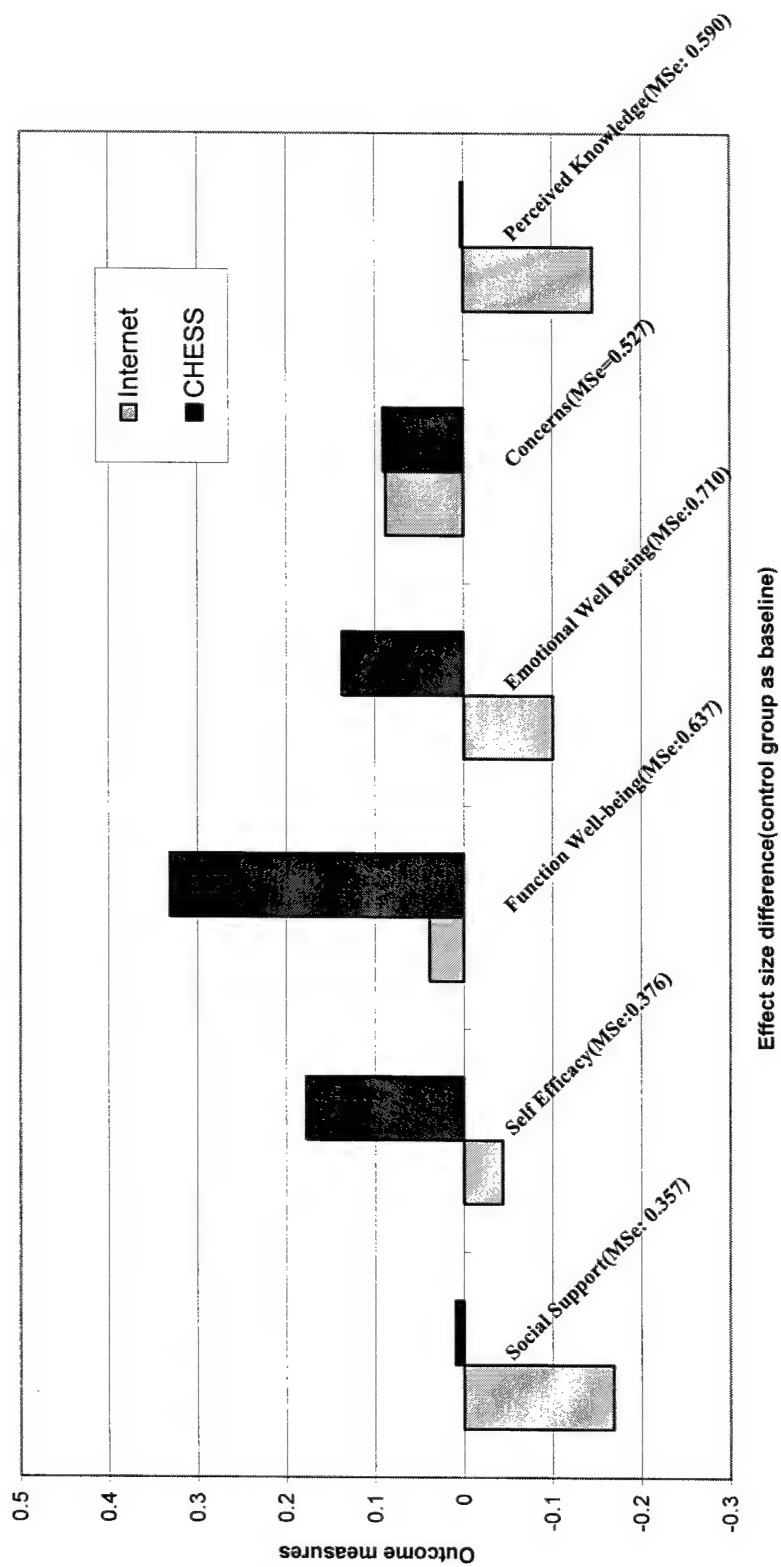


Figure 8
Effects Size, Interval ≤ 61 days, Covariate-Adjusted Means



E. Discussion

This research study produced an innovative computer-based decision support system (CDSS) that enables women to integrate the information available to them, understand diagnoses, treatment options, and risks associated with treatment options, construct and structure their preferences, and make important health decisions. We were able to assess the impact of the new CDSS by making it available to women newly diagnosed with breast cancer and comparing it with existing technology (the Internet) and a control group. The assessment of its impact was made in terms of understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status and change in quality of life.

Nearly all types of women with breast cancer were included: all ages, stages, treatments, and levels of education. Patients who are illiterate or have vision problems were not included in this study. And since our 3 sites vary geographically across the country, our results should be generalizable across most demographic features. This study population is similar to the population of most women with breast cancer: (1) The ethnic breakdown of the breast cancer population at study sites (75% Caucasian, 25% minorities) is similar to that of the U.S. as a whole (76% Caucasian, 24% minorities), (2) Sites include both public and private hospitals, (3) Subjects included patients from urban, small city and rural areas, and (4) from all socioeconomic strata, including low income patients without insurance, middle and upper income patients. However, our study will not generalize to patients treated in small, rural general surgeries.

This research highlights the need for providing timely decision support. Women who are diagnosed with breast cancer are faced with a number of significant treatment and non-treatment choices in a relatively short period of time and any delay in providing support that is intended just for decision making reduces the utility of such support. Of course, women who find themselves facing such a diagnosis need other types of support that go way beyond just decision support.

While CHESS users were more likely to retain their preferred decision making style over time, our study found little evidence to support the hypothesis that there was a difference in satisfaction with treatment decisions across the three groups. This lack of significant differences may be partly due to a ceiling effect. The results show that overall, women in the study were relatively satisfied with their decision making regardless of the form of decision support they received.

Furthermore, the results show that in order to provide support for decisions following a diagnosis of breast cancer, interventions must be

implemented as soon as possible. In this study, the number of women finding themselves in the situation of having decisions to make dropped off rapidly in the weeks following diagnosis. With such small numbers of women making decisions later in the intervention, only very large differences in decision satisfaction would be identified as statistically significant. This research has also shown that the existing decision satisfaction scales do not possess a high level of discriminatory power, at least for decisions involving breast cancer treatment. There was a high level of agreement with the statements, particularly those with a positive frame. Only the questions with a negative frame exhibited significant levels of disagreement. This does suggest that at least some subjects were not applying social desirability in their responses.

It is important to stress that the failure to identify statistically significant differences in levels of satisfaction with *decision* support does not mean that the technologies do not provide other kinds of support that maybe equally as important if not more important to women faced with a diagnosis of breast cancer.

For instance, CHESS had substantial impact on quality of life IF the patients receive CHESS relatively soon (less than 60 days) after diagnosis. Part of the reason for this may be that CHESS and Internet groups used their computers very differently. Although a computer session seems to take about the same time in the Internet and CHESS groups, the CHESS users logged on more frequently, spent more time dealing with health related information while the Internet users quickly left health related sites to go to non-health sites.

Prior to this study one might have argued that leaving health sites is good because women want to move on with their lives and spending time emailing to their grand children or shopping on line helps to them to do that. However our results suggest that such behavior is detrimental to their health.

Key Research Accomplishments

Several key research findings resulted from this research. They are listed below:

- CHESS users logged into their systems significantly more frequently than Internet users and spent more time on the computer. However the average time spent per logon was about the same.
- While computer use declined for both groups over time, Internet users entered non-health sites significantly more frequently than CHESS users but CHESS users were significantly more likely to enter health sites. These findings were particularly true during the first two weeks of access.
- Even after removing CHESS usage, CHESS users still entered health sites significantly more frequently than the Internet group
- When the analyses included all subjects (regardless of length of time between diagnosis and entry to study), the differences in quality of life scores between CHESS, control and the Internet groups was not significant, although the CHESS group improved more than controls on four of six outcomes and Internet improved less than controls on five of six outcomes.
- However, when only those subjects that entered the study within two months of diagnosis were included in the analyses the CHESS group showed significantly greater improvement than Internet on three quality of life outcomes and improved more than controls on all six outcomes while controls improved more than Internet on four of six outcomes.
- Women face many treatment and non-treatment decisions when they are diagnosed. The number of the decisions they need to make reduces over time (from 4.2 just after entry to the study to 2.4 at two months, the
- There were no significant differences between groups in terms of improvements in perceived knowledge, decision satisfaction or compliance with treatment decisions..
- However, the proportion of women who preferred to share decision making responsibility with their physicians remained relatively stable over time however a substantial proportion of women (29%) changed their preferred style over time.
- While no significant differences were found between study arms in desire to participate in decision making, there were significant differences in propensity to change decision making style. The Control group was more likely than the CHESS group to change their preferred style over time.
- Those in the CHESS group initially felt significantly more confused about what choices were best for them but over time that difference disappeared. However, the CHESS group also felt less of a need to consult other people in making their decisions, while the Internet group was significantly less confused about their options.

Reportable Outcomes:

Conference Presentations:

- The Summary Meeting of the NCI's Digital Divide Project
Bethesda, Washington
December 2, 2002
David H. Gustafson, PhD
"The Role of eHealth in Closing the Digital Divide"
- The National Library of Medicine Special Workshop Series on eHealth
Bethesda, Washington
October 10, 2002
David H. Gustafson, PhD
"How Women with Breast Cancer Use the Internet and How it Affects their Quality of Life"
- The APA Special Conference on Women's Health
Washington, DC
November 2002
Suzanne Pingree, PhD & Robert Hawkins, PhD
"Effective" Use of an Online Breast Cancer Information Support System"
- The eHealth Summit
Tempe, Arizona
November 9, 2002
David H. Gustafson, PhD
"How Women with Breast Cancer Use the Internet and How it Affects Their Quality of Life"
- Association of Internet Researchers
Maastricht, The Netherlands
October 16, 2002
Suzanne Pingree, PhD & Robert Hawkins, PhD
"Attempting to Bridge the Digital Divide for Breast Cancer Patients"
- **USAMRMC 2000 Conference**
Atlanta, Georgia
June 8-12, 2000
Francois Sainfort, PhD
"Impact of Information Technology on Breast Cancer Patient Decision Making"

Conclusions

This study was one of the first to document the myriad of decisions faced by women recently diagnosed with breast cancer and one of the first to document how women with breast cancer use the Internet. It also raises the question of the value of the Internet in helping women with breast cancer. In particular the study found little evidence that those who had access to the Internet improved in quality of life or decision satisfaction. If anything the Internet seems to reduce improvement in quality of life compared to control groups. Although further study is needed, there may be many reasons for this finding. The Internet possesses enormous amounts of potentially conflicting information of varying quality that can only be obtained by accessing sites with many different interfaces that require time to learn and can be frustrating to use. The motivation of the developers of the sites range from a commitment to quality to a commitment to make money whatever it takes and sometimes it is difficult to tell which sites are driven by what commitment. Most sites have little evaluation. Conversely, CHESS uses one interface and while it contains less information, it is still a substantial amount. CHESS is a non commercial program developed by university researchers based on extensive studies of user needs and evaluated in several studies. It appears that users can tell the difference and that those differences influence outcomes.

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Appendix 1: CHES Home Page

CHES Living After Breast Cancer - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Search Favorites Media

Address: https://ches.chsra.wisc.edu/bcancer/Topics/Home.asp

Go Links

Living After Breast Cancer Diagnosis

CHES

BC Topics Message Center Health Tools Other Sites My Folder Search

Dictionary Exit

Select a Breast Cancer Topic

Breast Cancer Basics
Basic information about what breast cancer is, causes & detection.

Surgery
Information about surgical options, risks, & recovery.

Other Treatments
Information about chemotherapy, radiation, tamoxifen, clinical trials, & complementary treatments.

Personal and Family Care
Support information & resources for you and your family.

Recurrence/Metastasis
Information on treatment options and managing emotional concerns.

Pain
Information on managing cancer pain (through medicine and visualization).

If Treatments Stop Working
Information about hospice & end of life decisions.

Money & Legal Concerns
Information about financial & legal resources to help you cope with breast cancer.

Dealing with the Health Care System
Information on how to be an active participant in your health care.

Your Messages
January 23, 2003
Ask an Expert: 0
Discussion Groups: 148
CHES Friend: 0

Today's Health News
Medline Plus; Latest News
Cancer Trials; News and Features
BreastLink.org

? Need help?
Go to the CHES Guide.
Click on this icon to get help

Start | Inbox - Microsoft Outlook | CHES Living After Bre... | Internet | 8:48 AM

Appendix 2:

List of Website for Internet Only Group

Below is a list of several Websites, the Web address (or URL), and a brief description of the site:

Name of Website: National Cancer Institute

Web Address: <http://www.nci.nih.gov/>

Site description:

At the Cancer Institute's website, you'll find cancer information and patient education publications on a variety of topics.

Name of Website: Komen.org

Web Address: <http://www.komen.org>

Site description:

This website provides information about education, screening, research and treatment for breast cancer. It targets women with breast cancer, their families and those who support them. It also seeks to educate the public about breast cancer and the issues surrounding the disease.

Name of Website: Celebrating Life Foundation

Web Address: <http://www.celebratinglife.org/index.html>

Side description:

This website contains breast cancer information, questions and answers, breast self-examination, stories from breast cancer survivors, and activities and events. This site particularly targets African American women and women of color.

Name of Website: Y-ME National Breast Cancer Organization

Web Address: <http://www.y-me.org>

Site description:

This website provides information about breast cancer and resources to turn to for support and further assistance. Services include Frequently Asked Questions (FAQ), Survivor Stories, Y-ME Newsletter, Y-ME Publications, Question Forum, and Links to other sites.

Name of Website: American Cancer Society

Web Address: <http://www.cancer.org>

Site description:

Provides information on American Cancer Society (ACS) programs and events and local ACS Chapters as well as comprehensive information about diagnosis and treatment.

Name of Website: OncoLink

Web Address: <http://oncolink.upenn.edu/>

Site description:

OncoLink is affiliated with the University of Pennsylvania Cancer Center. OncoLink provides information on many types of cancer. Some of the areas covered include Frequently Asked Questions and Answers about Cancer (FAQ), Cancer Causes, Screening and Prevention, Clinical Trials, and Global Resources for Cancer Information.

Appendix 3:

Recruitment and Training Protocol

Protocol for DOD Study:

Recruitment
CHESS/Internet Training

The Site Coordinator / Study Introduction:

The site coordinator/recruiter plays an important role in making the patient feel comfortable in the midst of hearing very difficult news. Site coordinators/recruiters are chosen for their sensitivity to people in crises, their belief in research, and their excitement for the CHES project. (To date, we have had very effective results in breast cancer patients accepting being part of a CHES study upon diagnosis, with approximately an 80% acceptance rate).

The site coordinator/recruiter begins by reintroducing themselves to the patient and acknowledging the fact that this is a very difficult time for the patient. They go on to explain briefly about the research project and ask if the patient would like to be willing to have the CHES Project Director give them a call to explain the study in more detail.

Suggested Explanation of Project to the Patient by the Study Coordinator:

"I'm _____ (your name), the site coordinator for a research project funded by the Department of Defense. I will just take a minute of your time to mention a study that you might be interested in getting more information about."

"All patients who are within two months of diagnosis for breast cancer are eligible for the study, except for those who are less than 18 years of age, those who are homeless and those who cannot read. Do you fall into any of these categories? I don't need to know which one."

YES: "Thank you, but I'm afraid this study won't be appropriate for you.
Thank you for your time. I'll let the nurse know that you are waiting for her."

NO: If patient answers no, continue to next section.

Brief Explanation of the DOD study:

"In this study funded by the Department of Defense, we are trying to see what kind of information and support is most helpful to patients diagnosed with breast cancer and in what format. Women involved in the study will be randomly assigned to one of four groups in which they will get one of the following: a set of books about breast cancer, a set of audio tapes about breast cancer, and two of the groups will get access to information about breast cancer via a laptop computer with Internet access. In return you will be asked to fill out several surveys. You will get some financial compensation for filling out the surveys. If you think you might be interested in this study, I can have the Project Director, Fiona McTavish give you a call and explain the study in further detail to you. Do you think you are interested?"

YES: "All I need to do right now is have you sign the consent form that gives me permission to have Fiona (the Project Director) call you."

Give patient the consent form to fill in and sign.

NO: "I appreciate your time and wondered if you might be willing to answer just a few quick questions that we ask those who decide not to be on study? You are under no obligation to answer it if you would rather not."

YES: ask the Declined to be in Study questions

NO: "I appreciated the opportunity to talk with you today."

Project Director Protocol for phone conversations:

"Hi my name is Fiona McTavish from the University of Wisconsin Madison. The study coordinator _____ at Sinai Samaritan asked me to call you regarding your interest in the study that we are running for women newly diagnosed with breast cancer. Thanks for your interest in this study. Is this a good time to explain the study to you?"

NO: "When would be a good time to call you back? I'll try back at that time. Thank you."

YES: "Great, I'll go ahead and explain the study to you. Please feel free to ask any questions as I go along. This study is a federally funded study, funded by the Department of Defense. We are trying to see what kind of information and support is most helpful to patients diagnosed with breast cancer. The study has four groups. All of the groups will receive information about breast cancer, but they will get the information in different ways. The first group will get a set of audio tapes called *The Cancer Survivor's Toolbox*. Tape recorders will be available for those patients who need them. The second group will receive any or all of the following books: *Dr. Susan Love's Breast Book*, written specifically for women with breast cancer; *Breast Cancer? Let Me Check My Schedule*, a book written about the experiences of ten professional women who all experienced breast cancer; and *Celebrate Life*, a book that highlights about 40 stories of African American women dealing with breast cancer.

The third and fourth groups will get information about breast cancer by having a computer placed in their home for five months. One of the groups will get a computer program called CHES. CHES stands for the Comprehensive Health Enhancement Support System. CHES has a variety of services in it, including up to date information about breast cancer and the ability to be connected to other women who have breast cancer. Also, since CHES uses the Internet, they will also receive free Internet access as well. The other group will get a computer that only has Internet access. Both services will be provided at no cost to the participants.

No computer experience is necessary to be a part of this study. We will provide training on both systems. The computer will be in your home for 5 months. There is no cost to you! Again, don't worry if you know nothing about computers, **absolutely no computer experience is needed.**

I cannot guarantee which group you will be in as people are randomly assigned to one of the groups. If you are in a group that gets a computer, there will be a training session provided. Each participant who gets the computer is given a code name to ensure their anonymity. As I mentioned to you earlier, this would not cost you anything. Since the computers are laptops, the only thing you will need to have at home is an electrical outlet to provide power to the computer and a phone jack in order to connect to the Internet.

Each person agreeing to be in the study regardless of which group they are in will be asked to fill out a total of seven surveys. You will be reimbursed for every survey you fill out. The surveys will be mailed to you. There are three short surveys which will take about ten minutes each. You will get \$5 per survey for filling those out. The others are longer and will take about 20-30 minutes to fill out. You will get \$15 for each of the longer surveys. You will be reimbursed a total of \$75 over the course of the study. There are self addressed envelope to send the surveys back in. Other than filling out these surveys you have no other responsibilities to this study. Also, your survey answers remain anonymous. If you decide to participate in the study, you are assigned a number, which is the only identification on any data we collect. I will be the only person who has access to both your name and code number. This information will not be accessible to anyone else. It will be kept in a locked file drawer in my office.

This research study will not affect the treatment you receive in any way. Your doctor will not know whether or not you agreed to be in the study. There is absolutely no cost to be involved in this study, as mentioned earlier you would gain a total of \$75.00 just by filling out the surveys.

Do you have any questions about the study? (Answer any questions that arise)

Do you think you would be willing to be part of this research study?"

YES: "Great, what I will do is sending you the first survey immediately, along with a copy of the consent form. Once you have sent those back in the self addressed envelope, I will open up the envelope which lets us know which group you are in. I'll be in touch with you then so we can get either get you the books, audio tapes, or set up a time to bring out the computer and set that up for you. Thanks again and if you have any questions don't hesitate to call me at 1-800-361-5481. I'll send out the survey and consent form this afternoon.

NO: "I appreciate your willingness to take the time and hear about the study. Would you mind if I ask you ask you a couple quick questions about why you didn't want to be on study? This will only take a minute."

YES: Ask question on decline to be on study sheet

NO: "Thank you very much for your time. I appreciate it very much."

RANDOM ASSIGNMENT:

Once the pre-test is returned, the subject will be randomly assigned to one of the groups. The envelopes for random assignment are in numerical order and must be opened in order. The number on the envelope will be the person's code number. Open an envelope from the appropriate set to determine which of the following groups the research participant will be assigned. Mark this information on the tracking sheet, which you have for the participant. If she is in a group that gets a computer, when you inform her of which group she is in, schedule a training time with her. If she is in the group that gets the audio cassettes, make sure she has a tape recorder. If she does not have one available, offer one to her as part of the study. If she is in the control group, give her any or all of the following books: Dr. Susan Love's Breast Book; Breast Cancer? Let Me Check My Schedule; and Celebrate Life. No matter which group she is in let her know you will call her in a week to see how she is doing.

A: Control Group:

If she is assigned to the Control Group the Project Director will call the subject and let her know she is in the control group. She will then be asked if she would like all the books or simply a selection of the books (Dr. Susan Love's Breast Book; Breast Cancer? Let Me Check My Schedule; and Celebrate Life). The books will be sent to the study participant that same day. She will also receive a phone call one week later to answer any questions and make sure she received the books.

The Project Director will also let the study participant know that she will receive \$15 for completing the pre-test survey. Mention that the next survey will come in the mail in two weeks, and that the next few surveys will come at two-week intervals so there will be quick turn around time between filling out the surveys and getting the next one. The name of the study participant should not appear on the survey or on the return envelope.

B. Audio Cassette Group:

If the study participant is assigned to the Audio Cassette group, the Project Director should make sure she has a tape recorder available. If she does not, the site coordinator will offer her one as part of the study.

Like the other study participants, the experimental group will receive a phone call from the site coordinator one week after joining the study to make sure they are doing okay.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey. Mention that the next survey will come in the mail in two weeks.

C. Computer Groups:

If the study participant is assigned to one of the groups that get a computer the site coordinator will set up a time to train them in the clinic that day, if possible. They should spend 45 minutes to an hour training them. The site coordinator will need to set up the Internet connection before the computer can be used in the home.

The research project will pay for the Internet connection for the five months that the computer is in the home. When the computer is removed from her home (5 months after installation), the Internet connection will be disconnected.

Like the other study participants, the computer group will receive a phone call from the site coordinator one week after joining the study to make sure they are doing okay. This also allows the site coordinator to answer any questions the participant may have regarding the study in general or questions they may have regarding the computer.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey. Mention that the next survey will come in the mail in two weeks.

Site Coordinator Protocol for Interaction with Study Participants:

The Project Director (or Madison Site coordinator) will call all research participants (regardless of which group they are in, experimental or control) one week after initially joining the research study to see how she is doing and ask if she has any questions regarding the study.

General Phone Call Etiquette:

- Introduce yourself and remind the study participant that you are the research site coordinator that they met at the hospital.
- Ask if this is a good time to talk or should you call them back at a later time?
- Ask how they are doing, feeling ...
- Ask them if they have any questions regarding the study.
- If the phone call is regarding post-test surveys, ask the participant if they received the survey, and remind them to fill it out and return it as soon as possible.
- Thank them for their time and let them know they can call you if they have any questions.

UW Madison Phone Calls

The UW Madison will call all research participants three days after sending out the two, four and six week surveys. The purpose of this phone call is to be sure that they received the survey and to remind them to complete it and send it back in the pre-addressed envelope. The site coordinator should call the participants one-week after sending out the two-month, four-month and nine-month post-tests. If the post-test survey is not returned within a week, a second phone call will be made and a second survey will be mailed out if necessary. If the survey is still not returned within another week, the site coordinator will try to collect the data by phone interview.

Installation Protocol:

The site coordinator will install computers in the patient's home. The following is an outline of the installation process, followed by an outline of how to walk a person through CHESS and/or the Internet for the first time.

Computer Installation: Phone call to Arrange Installation Time:

- 1. Re-Introduction**
 - a. Name
 - b. Connected with Mayo Clinic, CHESS Research Project - funded by DOD
- 2. Hardware Requirements**
 - a. Electrical Outlet
 - b. Phone Jack
- 3. Information Installer Needs**
 - a. Rotary or Touch-tone Phone lines
 - b. Call Waiting? Y/N
 - c. Is it long distance to the city where the Internet provider is located? Y/N
 - d. Ask the user to choose a codename and password. Explain to them that each time they use CHESS they will need these codes to "log in." These also assure the user of anonymity. Suggest that they write these codes down on a piece of paper and put them in a safe place so they have them in case they forget them.
 - e. Time and Date to install computer
 - f. Explain that installation usually takes about an hour
 - e. Get directions to house if the installation will be in the home
 - f. Complete address (zip code and phone number and correct spelling of name.)
- 4. Restate date and time of Computer Installation or training in the clinic**

CHES: Pre-Installation Checklist for Installer

1. CHECKLIST

- 0 Set up an Internet connection.
- 0 Enter the codename and password of the person before the installation date. To do this, go to <http://chess.chsra.wisc.edu/admin/>. This will take you to the Remote Administrative Tools section.
 - 1. Login using **codename:** dod and **password:** Thistle.
 - 2. Select the Living with Breast Cancer Module.
 - 3. Select a chapter (in this case, DOD).
 - 4. Choose Add a New User.
 - 5. Put in the pertinent information on the *Add a New CHES User screen.
*make sure to always mark NO for the CHES Expert because that is only marked YES if the person being registered is the one who answers the Ask and Expert question as the Expert.
 - 6. Choose the discussion groups the woman will be allowed to use.

CHES: Computer Installation

1. Equipment to Take:

- 2 laptops with carrying cases
- 1 power cord for the laptop
- 1 Telephone line cord
- Telephone cord extension adapter
- Telephone line adapter (splitter)
- 2 to 3 prong electrical plug adapter
- mouse

2. Misc. Items to Take:

- CHES Breast Cancer User Support Materials
- For the patients who receive Internet only, bring the information about the Web to leave with them.
- Telephone number, address and directions to participant's home
- Help Line phone number (1-800-480-9223) in case there are any problem
- Map of the area

3. Setting Up the Computer

- a. Ask where computer can be placed
- b. Find telephone jack
- c. Find electrical outlet
- d. Set up computer (This should take about 5 minutes)

**Always take an extra Laptop with you
just in case there is any trouble with the original one.**

**Be sure you are comfortable with setting up
computers before taking one out to install!**

1. WALKING THE PERSON THROUGH CHESS AND/OR THE INTERNET

(This should take 40 to 50 minutes. If other family members are there and want to be involved it will take approximately 10 more minutes).

- a. **Reassure** the person that no computer experience is necessary and that everything you will be telling them is in the User Support Materials and on the computer screen. They can also call you or the Help Line (1-800-480-9223) if they have any questions.
- b. **Turning on the computer**
Use the power switch on the laptop to turn the computer on.
- c. **Describe the keyboard and mouse** to the user. Explain to them that while there is a finger mouse provided on the laptop, we will also give them a separate mouse, which may be easier for them to use. ****Remember that the external mouse needs to be plugged prior to turning on the computer.** Have the user sit down at the computer and use the keyboard and mouse as you walk them through CHESS. If they have never used a mouse before, let them use it to get a feel for how it works before you begin.
- d. **Show her how to log on to CHESS** using her code name and password.

2. TRAINING FOR THOSE WHO RECEIVE CHESS WITH INTERNET ACCESS:

To begin training, click on the browser icon on the desktop. The CHESS Start page will come up. Using the CHESS site, begin the training by going over some basic Internet skills. **Sign on with her codename and password to begin training.**

- a. **Explain** the navigation functions of the browser:
 - **Back/Forward Button**
The BACK and FORWARD buttons are located on the browser toolbar at the left hand side of the screen. The BACK button allows the user to jump back to the previous screen you were viewing. The FORWARD button allows them to move forward in the same way.
 - **Scroll Bar**
Show the user how to move the screen up or down by either clicking on the bar with the left hand mouse button and dragging the mouse up or down or by using the arrows at the top or bottom of the screen.
 - **Home**
Explain to the user that this will always bring them back to the CHESS Home Page.
- b. **Highlight** the fact that when the cursor moves over a link, it changes from an arrow to a hand. This will help the user find links when they are in the form of pictures or other graphics.
- c. **Show** the user the way that a hyperlink changes color when they have already visited it.
- d. **Show** the user how to use the mouse and click into a search box in order to begin typing the words for the search.
- e. **Demonstrate** how to use the search engine Alta Vista (www.altavista.com). Use the help section provided on the page to show the user different ways to search and then try searching for something they are interested in. A suggestion would be to have them search for "dogs", and then, to narrow the search, search for "police dogs." This will give them an idea of how many entries will can come up for a general topic, as well as how to narrow their search topic.

Next, move on to the CHESS specific navigation of the **Tool Bar**. After the explanation of each section, click on the word to give the user an idea of what happens in each section of the Tool Bar:

- a. **Topics** This section allows you to search CHESS by specific topics such as treatments, menopause, emotional support or pain. You can click on a word and select a topic you are interested in finding out about.
- b. **Dictionary** CHESS has a dictionary of words that are medical and/or technical in nature that relate to breast cancer. By clicking on the Dictionary button on the toolbar, you can find the meaning of words you may not be familiar with.
- c. **Bookmarks** This section of CHESS allows you to "mark your place" and come back to information you may be particularly interested in.

- d. Keywords** To search for a specific topic by keyword such as, menopause, emotional support, or pain, click the Keyword button on the toolbar. The keywords are organized using the alphabet. You can click on a letter to see the list of keywords that begin with that letter. To search for a specific keyword, type the word into the search box provided. You can get a complete list of the keywords by pressing the search button without typing anything in the box.
- e. Help** You can click on the Help button no matter where you are in CHESS and information for that particular part of the website will come up.
- f. Services Menu** Show that the CHESS Services are divided into 8 areas (Overview of Breast Cancer, Decisions and Planning Guides, Personal Space, What's New, Reading Room, Other Sites, Connecting with Others, and Beginners Guide). Click on Beginner's Guide. Show how to get descriptions of each service by moving the mouse over the service.

3. EXPLAINING THE CHESS SERVICES:

Using the Services link at the lefthand side of the screen, take the user back to the Services page. From here, explain the services provided on the website. The following list is **IMPERATIVE** to go over in detail with the participant. The other services can be touched on verbally in the course of the training session.

a. Overview of Breast Cancer

This section is provided to help women who have been recently diagnosed with breast cancer and who are just beginning the search for information about the disease. It contains basic information about breast cancer and the treatment options available.

Click into Overview of Breast Cancer and click on the first link in the list, Breast Cancer Basics. Read the short paragraph provided. Click on the middle photo to watch the video clip of Linda. Take the opportunity to show the woman where the volume control is on the computer. You will need to turn it up. Once you have viewed the video, use the back button. Show the user the options to look at Questions and Answers, Instant Library and Personal Stories that relate to the basics of breast cancer. Go quickly and show them the list of questions that are available in Questions and Answers, the list of articles in Instant Library and the list of Personal Stories. Explain that this is a condensed list, but that they could click on any of the Q/A to go directly to that question... Return to the Services menu by using the Navigation Bar.

b. Questions and Answers

Questions and Answers provides answers to the most commonly asked questions by women with breast cancer, their partners, and family. There are about 500 questions in the breast cancer module.

The user can look up questions through topics, such as diagnosis, treatments, prevention, emotions..., or they can use the Search function and type in a word they are interested in knowing more about. The search will bring up a list of questions that include that particular word. Ask the woman to whom you are demonstrating CHESS to click on the link to Questions and Answers.

Have the woman click on the word "Treatments." This brings up another list of options, from which she should choose "Surgery", and then "Questions to Ask Before Surgery". Have her choose the question "What questions should I ask Before Surgery?" and let her read the answer.

At the bottom of the page, there is a list of keywords. Explain that she can click on a keyword to get more information relating to the topic of the question. Have her choose the keyword, Doctors, Communication With. A box will appear telling the user which CHESS services have information on this topic. Click on the button for Instant Library. You will see a list of articles about talking to your doctor. Click on Talking with Your Doctor (middle of the list). The computer will take her to that article. Explain that once the user has finished reading the article she can go to other CHESS Services that have information on that same topic or return to Questions and Answers. Return to the Services page by using the back button or clicking on the Services Menu link on the top left of the screen on the Navigation Bar.

c. Web Links

Next take the user to the Web Links section from the Services page. Explain to the user that Web Links is a list of web sites that the developers of CHESS have reviewed for content and reliability.

Click on Web Links and a list of web sites will come up. Have the user click on American Cancer Society. This will take you to a page with some information about the website. Go over this information with the user, explaining that the information is provided to give them basic information about each site we provide as Web Links.

Click on the URL link (which is the address of the site) to take you to the American Cancer Society site. Explain to the user that they have now exited the CHESS site and are now at the American Cancer Society website. Show them how they can return to CHESS by using the BACK button on the browser. Return to the Services page by having the user click on Services at the top left of the screen on the Navigation Bar.

d. Ask an Expert

This service allows the user to ask questions anonymously (the user is only identified by her code name) to an expert in the area of breast cancer. Questions can deal with issues such as medical, social, financial, spiritual, emotional... Explain to the user that the Expert works with a group of experts in various fields who can assist in answering questions that she may not be trained to answer. Questions are answered within 2 business days.

Have the user click on "Ask an Expert". Then have her click on "Ask the Expert A Question." A blank box will appear on the screen. Have her type "Who Are the Experts?".

Next, have her click on "Read Answers to Your Questions." The Welcome Message from the Expert should show up. Have her read the welcome message. Explain that if there are no new messages, it means the expert hasn't answered it yet. If she does not get a response from the Expert within 2 business days she should call the Study Coordinator so she can check to see that there are no computer problems.

During this time, you should also show the user the Open Expert messages. Explain that when the Expert gets a message from a woman that she feels is applicable to the entire group, she will take out all identifying information and will put it in the Open Expert section so everyone can read it. Show her how to use the keywords to look in the Open Expert section for topics she is interested in. To return to the Services page, click the button on the upper left of the screen.

e. Discussion Group

Explain that Discussion Group is a service that allows the user to talk confidentially and anonymously to other people who have access to the CHESS computer. There are several discussion groups which the user can take part in by reading and/or writing messages. The discussion groups are anonymous. No

one knows the user's real name, they only know each others' code names unless a user reveals their real name.

CHESS offers two types of Discussion Groups, World Groups and Local Groups. The World Groups can be used by anyone who has access to CHESS. Patients in specific local areas, as well as in different research studies will use Local Groups. Local groups are limited to approximately 40 users. The installer should set up which Local and World Groups that the user can be a part of before beginning the training.

If a family member wants to use the CHESS system, they need to get a codename and password from the site coordinator. They are more than welcome to use the system once they have these things.

Sending messages in Discussion Group works the same way as Ask an Expert. To read through messages, click on "Read New Messages." Any new messages will automatically appear on the screen (this might take a few moments the first time depending on how many messages there are). A list of all the messages will then appear on the screen. The newest messages will be on the bottom of the list. Click on the message you want to view. The message will appear. To reply to a message click on the "Write" button at the top or bottom of the screen. A blank box will appear on the screen (just like in the Ask an Expert Service). Show her how to write and send a message. Type out a message similar to the following: "Hi, this is Fiona and Cadillac trying out the computer and learning how the discussion group works. Talk to you more later, Fiona and Cadillac" Before actually sending the message, ask the woman if it is okay that you send the message (it will appear with her codename). If she says yes, go ahead and send it. This allows other women in the discussion group to know there is a new person on the system and they can then write her a message.

You should also explain the Discussion Group Archives and Introductions at this time. Tell the user that the Archives work like the Open Expert questions, except the Discussion Group facilitators do the work that the Expert does for Ask the Expert by taking the identifying information out of the answers if they want to post them in the Archives. The Archives are also linked by keywords.

Introductions allows users to fill in some general information about themselves so others get a better sense of who they are. They can fill in as little or as much as they wish. Users will need to open a message in order to access Introductions. If the person who wrote the message also has an Introduction, the Introduction button will appear in the list of buttons on the message.

Encourage the study participant to send an Introduction later (they can do it now, but it takes up a fair amount of time – so I suggest they do it later). Click on the Services button to return to the Services page.

f. Decisions and Planning Guides

Briefly go through Decisions, Decisions with the woman. Decisions, Decisions is broken up into three categories: Decision Workbook, Learning From Others, and Dept. of Defense Breast Cancer Decision Guide. Begin by going through Decision Workbook with the user.

There are two decision tools in the Decision Workbook available for women with breast cancer. They are:

- Choosing a Surgery
- Chemotherapy

The program contains step by step instructions of what to do. Each step describes the various options and discusses the concerns for each option. The users are asked to consider each option against the concerns, which other women with breast cancer felt were important. They may also want to type in their own options and concerns. At the end they will be taken to a summary screen which combines all the options with the concerns they felt were important.

Learning From Others is also a decision making tool. It is made up of various women telling their personal experiences with different aspects of their breast cancer experience. The women tell their stories using video and audio so the users can both see and hear them. Be sure to show the women how to use the video capabilities.

g. Health Tracking

In Health Tracking, the participant can choose which health issues she wants to keep track of over time.

Click on Health Tracking so she can see the list of items she can track. Choose from the three lists (Physical Health, Social/Emotional or Health Risks) several items that she would be interested in tracking. Explain that she can change the items she is tracking at any time. Just pick a couple of items right now and let her go back later and do as many other items as she is interested in.

Click Move On at the bottom of the screen. This will take her to the beginning of the questions the program will ask about each item she has chosen to track. Go through the questions with her. When she has finished, show her the graph and how she gets more information...

To get to the graph click on See graphs of how our items vary over time. You will get an explanation of what comes next. Press Move On to get to the graph. Choose one of the graphs to look at. Explain that as she tracks things over time, the graph will display the changes. Use the Back button on the browser to go back to the last menu. This time, go to the keyword, instead of the graph. You will then see a list of services that have information specific to that word. This works the same as any keyword. When you are finished, click on Services at the top left of the page to get back to the Services page.

Briefly touch on the rest of the services verbally with the woman as you finish up the explanation of CHESS. Remind her of the information in Getting Started which will go over each of the services and how they can be of use to her.

4. TRAINING FOR THOSE RECEIVING INTERNET ONLY

To begin training, click on the Internet browser icon on the desktop. The Gateway Home Page will come up as the Home Page for the browser. To begin:

- a. **Explain** the navigation functions of the browser:
 - **Back/Forward Button**
The BACK and FORWARD buttons are located on the browser toolbar at the left hand side of the screen. The BACK button allows the user to jump back to the previous screen you were viewing. The FORWARD button allows them to move forward in the same way.
 - **Scroll Bar**
Show the user how to move the screen up or down by either clicking on the bar with the left hand mouse button and dragging the mouse up or down or by using the arrows at the top or bottom of the screen.
 - **Home**
Explain to the user that this will always bring them back whatever they have chosen as their home page.
- b. **Highlight** the fact that when the cursor moves over a link, it changes from an arrow to a hand. This will help the user find links when they are in the form of pictures or other graphics.
- c. **Show** the user the way that a hyperlink changes color when they have already visited it.
- d. **Show** the user how to use the mouse and click into a search box in order to begin typing the words for the search.
- e. **Show** the user how to change their Home Page by changing it from Gateway to Alta Vista (www.altavista.com).
- f. **Demonstrate** how to use the search engine Alta Vista (www.altavista.com). Use the help section provided on the page to show the user different ways to search and then try searching for something they are interested in. A suggestion would be to have them search for "dogs", and then, to narrow the search, search for "police dogs." This will give them an idea of how many entries will can come up for a general topic, as well as how to narrow their search topic.

At the end of the training, highlight the information you will be leaving with them making sure they know they can refer to it if they have any questions, as well as for suggestions of good websites to visit.

5. TURNING OFF THE COMPUTER

Explain that when the user is finished using CHESS and wants to turn it off, she should first click the Exit button on the tool bar. This will return her to the "Welcome to CHESS" screen.

The user should then double click on the two attached computers down in the bottom right hand side of the screen. A box will appear called "Connected to CHESS Internet." She should click "Disconnect" in order to disconnect her computer from the Internet.

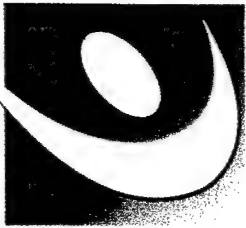
To turn off the computer she should click on the "Start" button on the lower left hand corner of the screen. Then she should click once on "Shut Down." Another message will pop up and she should choose "Yes" to shut down the computer.

At this point have the user start up the computer and log in using their own code name and password just to be sure that they know how to start it up. Once they get logged on, have them exit and turn off the computer.

6. OTHER INFORMATION

- a. Ask the woman you are showing the computer to if she has any further questions.
- b. Be sure that your name and number is written down on the instruction sheet in the folder. Reassure her that she can call you if she has any questions, needs any help, or is having trouble.
- c. Tell them that you will give them a call in about a week in order to make sure everything is going okay.
- d. If they have received CHESS, reiterate that you would like them to write a note in the open discussion group within the next few days in order make sure that their computer is working properly. They can write a real message or simply write "this is a test."
- e. Thank them for their time!

Appendix 4:
CHESS User Manual

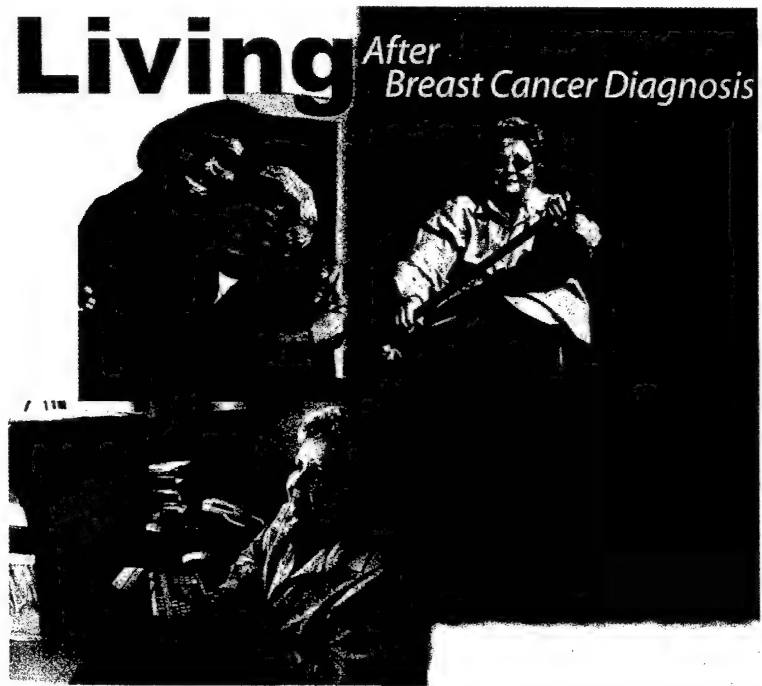


CHESS

Comprehensive Health
Enhancement Support System

USER SUPPORT MANUAL

Living *After Breast Cancer Diagnosis*



<http://chess.chsra.wisc.edu/bcancer>

TECHNICAL SUPPORT: 1-800-480-9223
Mon.-Fri. 8:30 am-4:00 pm, Central Time

GENERAL HELP: 1-800-361-5481



CHESS

LIVING AFTER BREAST CANCER DIAGNOSIS
<http://chess.chsra.wisc.edu/bcancer>

CONTACT INFORMATION

LIVING

After Breast Cancer Diagnosis

<http://chess.chsra.wisc.edu/bcancer>

*Developed at the University of Wisconsin-Madison
Center for Health Systems Research and Analysis (CHSRA)*

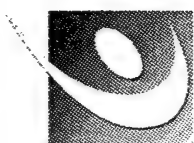
Your CHESS Installer: _____

Your CHESS Codename: _____

Your CHESS Password: _____

TECHNICAL SUPPORT: 1-800-480-9223
Mon.-Fri. 8:30 am-4:00 pm, Central Time

GENERAL HELP: 1-800-361-5481

**CHESS**

LIVING AFTER BREAST CANCER DIAGNOSIS

<http://chess.chsra.wisc.edu/bcancer>

FIRST TIME USER CHECKLIST

The first time you use CHESS on your own, please follow these steps that will help you “get to know” your CHESS support system. Microsoft’s Internet Explorer 4.0 (or newer) is the preferred browser for viewing CHESS. If you experience problems, call the Technical Support Line at 1-800-480-9223.

1. Go to the CHESS Guide, an online tutorial to help you use CHESS.

Follow these steps to go to the CHESS Guide:

Go to the BC Topics Page (this is the first page that appears after you login and have filled out your health tracking).

Click on Need Help? in the lower right side of the screen.

A window will pop up saying “Welcome to the CHESS User’s Guide.” There are four options listed: Demo, Intro, Lesson 1, and Lesson 2. Click on **Lesson 1**.

A short audio will play, which will show you the basic steps to use CHESS.

When the audio is finished, click on **Exit** in the upper right hand corner of the CHESS Guide window to exit the CHESS Guide.

2. Go to the CHESS BC Topics page.

At the BC Topics Page, you will see each of the main topics: **Breast Cancer Basics; Surgery; Other Treatments; Personal and Family Care; Recurrence; Pain; If Treatments No Longer Work; Money & Legal Concerns; Dealing with the Health**

Care System and a brief description of what you will find under each topic.

Continue looking through the CHESS Topics by clicking on a topic. You will come to a page that will show you the specific areas covered under that main topic.

3. From the BC Topics Page, you can also get a quick look at Your Messages.

You can tell at a glance if you have any messages from Ask an Expert or Discussion Groups by looking at the number next to the group name. To read your messages, click on the number. You can also get to

your messages by going to the **Message Center** tab on the top of the screen. Some modules have a third service called My Friend, which you use the same way as the Discussion Groups and Ask an Expert.

4. From the BC Topics Page you will also see current news articles under Today's Health News that may be of interest to you.

5. And please remember!

Others in your household are welcome to use CHESS but they need their own separate codename and password. Please contact your CHESS coordinator at 1-800-361-5481 to obtain those.



CHESS

LIVING AFTER BREAST CANCER DIAGNOSIS
<http://chess.chsra.wisc.edu/bcancer>

HOW DO I USE A MOUSE?

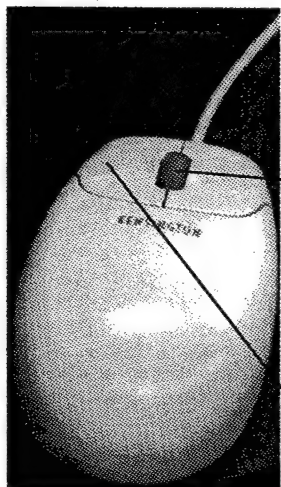


Figure 1

A mouse (Figure 1) is used to point to and click on items like buttons, hyperlinks or scroll bars on your computer screen. (To find out more about **hyperlinks** and **scroll bars**, see "What Do I Need to Know About the Screen?") Clicking on these items allows you to move from one place to another through the CHESS system.

If your mouse has a scroll (the small wheel shown on the mouse in Figure 1), you can use this instead of the scroll bar on the screen. Position your index finger on the wheel, then roll it forward or backward to move up or down the screen page.

To hold a mouse, place your hand lightly on top of it. If you are right-handed, position your index (pointer) finger on the left button and your middle finger on the right button. (The reverse if you are left-handed.)

The left button will be the one you click. *You will never have to click the right button when using CHESS.*

Move the mouse across a flat surface. As you move it, notice the **cursor** (either a small arrow or an "I" on the computer screen) moves the same direction.

Clicking on a Hyperlink or Button

To click on a hyperlink or button, move the mouse until the cursor on your screen touches the hyperlink or button you want. Depending on what you are pointing at, the cursor may change to a small arrow or hand. Click once with your left mouse button. This will take you to the related pages.

Clicking on the Scroll Bar

To scroll (move) the page up or down on the screen, move the mouse until the cursor touches the scroll bar. (Figure 2) There are two ways to scroll.

1. Using the up or down arrows

Position the cursor on the arrow above or below the gray bar.

Click the left mouse button. This will move the page up or down, depending on which arrow you click on. For example, to see the top of the page, click on the up arrow.

2. Using the sliding bar

Position the cursor on the darker gray bar.

Press and hold the mouse button, and drag the bar in the direction you want the page to scroll (e.g. to see the bottom of the page, pull the bar downwards).

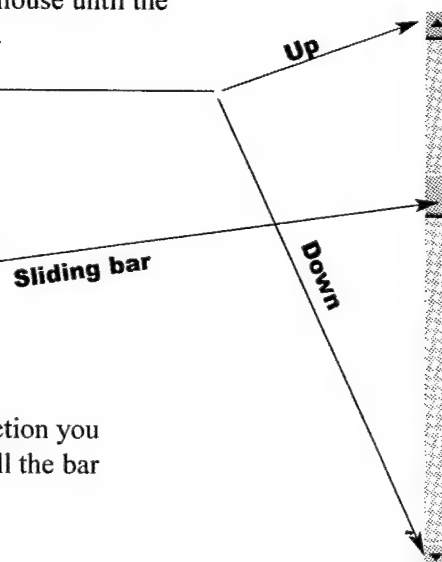


Figure 2



CHESS

LIVING AFTER BREAST CANCER DIAGNOSIS

<http://chess.chsra.wisc.edu/bcancer>

HOW DO I START?

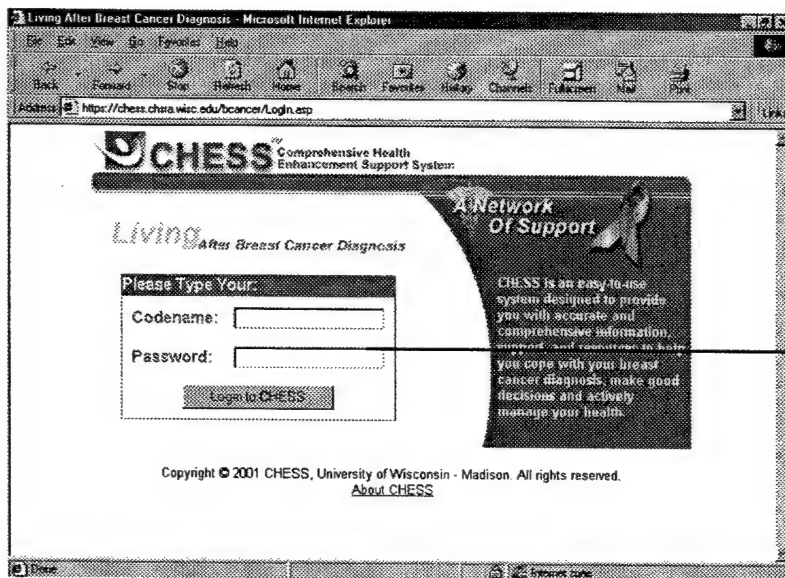


Figure 1

When you first turn on your computer, you will be asked for your CHESSE codename and password (Figure 1). Type those in the spaces provided.

Once you click the "Login" button, the computer will dial your phone to connect to the Internet. While it is connecting, you will see this message (Figure 2). The computer should connect automatically, so you should not have to click on any buttons just yet.

On rare occasions the computer might forget your Dial-up User Name and Password. If this happens, you will see a screen that indicates you entered an "invalid user name or password."

If you experience any problems with this, call the CHESSE help line at 1-800-480-9223.

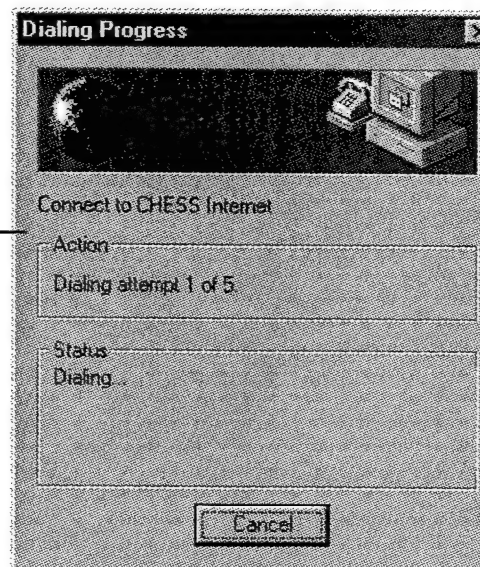


Figure 2

**CHESS**

LIVING AFTER BREAST CANCER DIAGNOSIS
<http://chess.chsra.wisc.edu/bcancer>

WHAT DO I NEED TO KNOW ABOUT THE SCREEN?

To view anything on the Internet (also known as “the Web”), your computer needs a browser. Think of a browser as a window through which you look, to view what’s “out there” on the Internet. The browser connects to the Internet through your phone line. Microsoft’s Internet Explorer 4.0 (or newer) is the preferred browser for viewing CHESS. (See “How Do I Start?” for more information on starting CHESS.)

Handy Things to Know About the Browser Screen

Back takes you to the previous page (screen) you viewed.

Refresh clears your screen when you get a browser error message.

Forward returns you to where you were before you pressed “Back.”

Home takes you to the beginning of CHESS.

This button **minimizes** (hides) the browser.

This button **resizes** the browser, to cover half or all of your screen.

This button **closes** the browser and ends your CHESS session.

The **scroll bar** helps you move the page up or down to see parts that may be hidden. (To learn how to use the scroll bar, see “How Do I Use A Mouse?”)

Browser toolbar

The whole area above is your browser “window.”

This area **displays the pages** of a website (CHESS is a website.)

WHAT DO I NEED TO KNOW ABOUT THE SCREEN (continued)

Handy things to know about hyperlinks

Hyperlinks are words on a web page that link you to additional information.

Hyperlinks usually appear in another color. When you place your mouse cursor over (or "roll over") the hyperlink, the cursor changes from an arrow to a hand, and the words usually appear as underlined.

To find out more about a particular topic, place your cursor over the hyperlink, and notice how both the words and mouse cursor change appearance.

Now click the left mouse button once. This will take you to the next screen of related information.

Go ahead and try this with the following hyperlinks you will find on the CHESS BC Topics Page:

**Breast Cancer
Basics**

Surgery

Other Treatments

**Personal and
Family Care**

Recurrence

Pain

**If Treatments No
Longer Work**

**Money and Legal
Concerns**

**Dealing with the
Health Care System**

To return to the previous screen, click the "Back" button on the browser toolbar.

**CHESS**LIVING AFTER BREAST CANCER DIAGNOSIS
<http://chess.chsra.wisc.edu/bcancer>

GUIDE TO USING CHESS

Getting Around CHESS

There are three ways to move around CHESS: the BC Topics Page, the Web Browser and the Tabs.

The BC Topics Page (Figure 1) contains links to all topics in the CHESS website. The information in CHESS is divided into nine topics, with additional categories under each topic.

Web Browser: There are some simple tools on the Web Browser to help you move around CHESS.

The BACK and FORWARD buttons are located on the browser toolbar at the left hand side of the screen. The BACK button allows you to go back to the previous screen you were viewing. When you go to another website from CHESS, you can use your BACK button to get back to CHESS. The FORWARD button allows you to move forward.

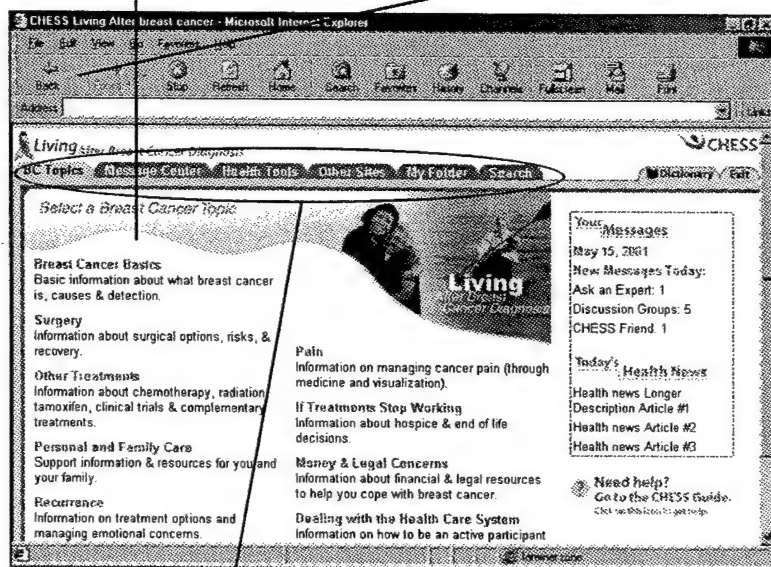


Figure 1

Scroll Bar: You can move the screen up or down by either clicking on the scroll bar with the left hand mouse button and dragging the mouse up or down or by clicking on the arrows at the top or bottom of the screen. (See "How Do I Use A Mouse" for more information on using the scroll bar.)

CHESS Tabs

There are eight tabs along the top of the CHESS screen. The tabs include:

BC Topics: Lists the nine topics in CHESS so you can easily find the information you are looking for.

Message Center: Takes you to "Ask an Expert" and "Discussion Groups."

Health Tools: Takes you to a variety of health assessment and decision aid tools.

Other Sites: Provides links to other websites that may be of interest to you.

My Folder: Your personal library and diary.

Search: Allows you to search the CHESS website.

Dictionary: Allows you to search for definitions of words used in CHESS.

Exit: Allows you to exit the CHESS program.

Getting Started: The web address for CHESS is <http://chess.chsra.wisc.edu/bcancer>. This will take you to the login screen (Figure 2). (If you need help getting to the login screen, see "How Do I Start CHESS?")

Codename and Password: Each time you enter CHESS you will be asked to enter your codename and password.

It is important to remember your codename and password. **Anyone else using CHESS in your home should have their own codename and password.** This provides both system security and protects your confidentiality. If you forget your codename and password, or if someone in your household needs a codename and password, please call the CHESS coordinator at 1-800-361-5481.

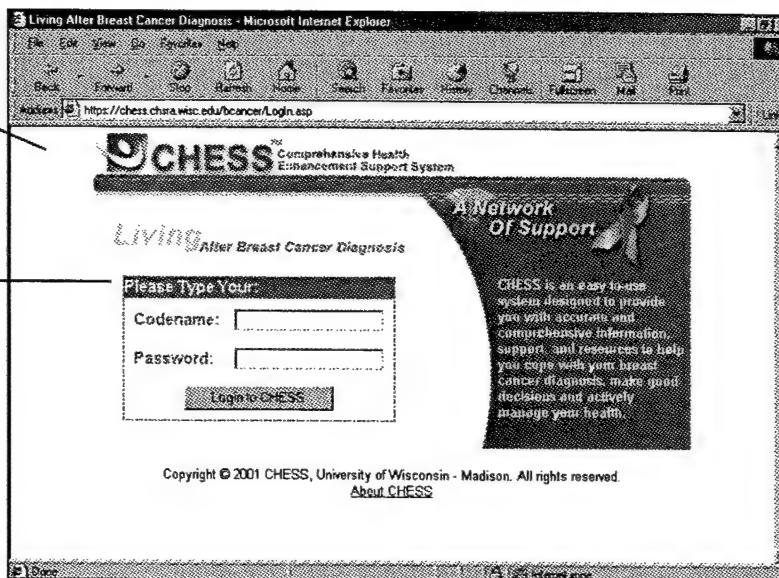


Figure 2

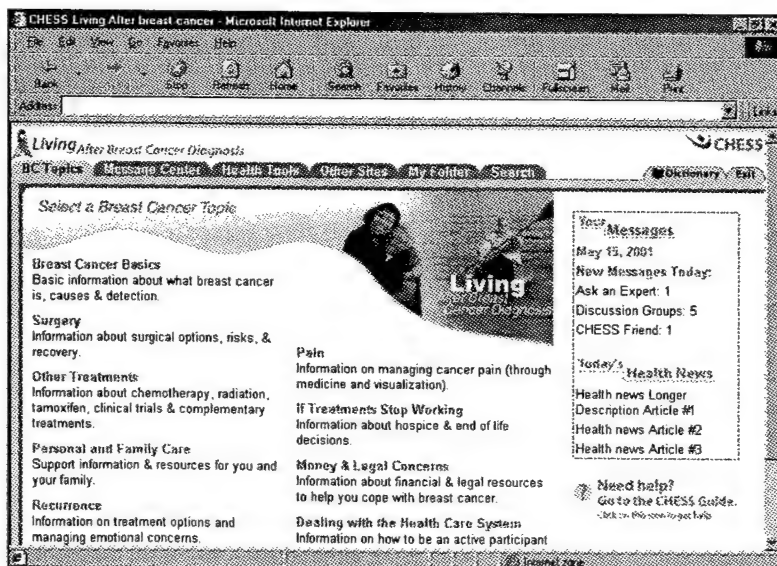


Figure 3

BC Topics: This is the first page you come to after logging into CHESS (Figure 3). It was also mentioned previously in "Getting Around CHESS."

From this page you can go to any topic in CHESS, including Breast Cancer Basics, Surgery, Other Treatments, Personal and Family Care, Recurrence, Pain, If Treatments No Longer Work, Money and Legal Concerns, and Dealing with the Health Care System. You can also access the CHESS Tabs, including Message Center, Health Tools, Other Sites, My Folder, Search, Dictionary and Exit.

Audio & Video: The CHESS website contains video clips of women sharing their personal experience with breast cancer. To watch the video (under Video Gallery), click on the text "See Her Video." A screen (Figure 4) will pop up. (Clicking on the text "See All Videos On This Topic" will take you to other video choices.)

Use the buttons provided on the video player. Click on the Play button to start the video; click the Pause button to stop it at any point along the way; or click the Stop button to stop the video. The video will start from the beginning after you click Stop, but will continue on from the point where you press Pause.

If your computer is not able to play video or broadcast audio, you will still be able to read the text of what the woman says in the video.

Melissa - Surgery Decision, Lumpectomy

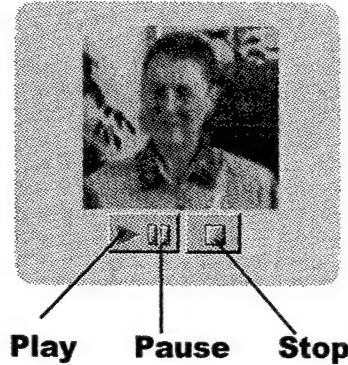


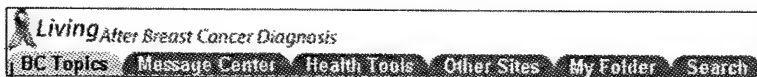
Figure 4

**CHESS**

LIVING AFTER BREAST CANCER DIAGNOSIS

<http://chess.chsra.wisc.edu/bcancer>

WHAT YOU'LL FIND IN CHESS



BC Topics

Lists all of the topics that are covered in CHESS, making it easy for you to quickly find the information you need. The topics include:

Breast Cancer Basics
Surgery
Other Treatments
Personal and Family Care
Recurrence

Pain
If Treatments No Longer Work
Money & Legal Concerns
Dealing with the Health Care System

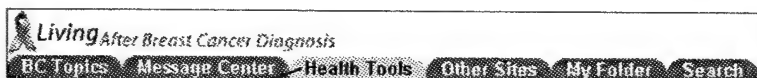


Message Center

Discussion Groups are on-line support groups which allow anonymous, non-threatening communication among people facing similar crises or concerns. You can share information, experiences, hopes and fears, give and receive support, and offer different perspectives on common issues. A trained facilitator monitors groups to keep discussion flowing smoothly.

Ask an Expert is a confidential and anonymous service that allows you to ask a question about your health, and get a personal answer from an expert within two business days.

My Friend is an e-mail system (only on some CHESS modules) that connects you to a person who will help you use CHESS, as well as support you through your breast cancer diagnosis.



Health Tools

Health Tracking lets you keep track of how you are doing physically and emotionally over time. By answering a few questions every other week you can see a graph of your progress as well as get links to other helpful information.

Action Plan offers a step-by-step guide to help you change your diet. It also helps you identify and overcome barriers that could stop you from succeeding.

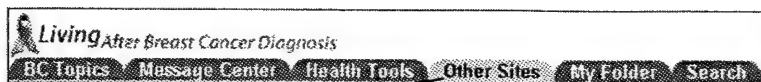
Assessments are tools to help you learn more about your diet. Answer simple questions, then get feedback on ways to improve your eating habits. There is also an assessment on mood.

Decision Notebook helps you learn about treatment options and concerns and allows you to figure

out which option best fits your life-style and values. A Summary Chart helps you organize your thoughts about the various options.

Learning from Others helps you think through a difficult treatment decision by listening to how other women have made theirs. It includes video clips and text of women telling their stories, to help you work through important things to consider.

DOD Breast Cancer Decision Guide is a website developed by the U.S. Department of Defense Breast Cancer Prevention, Education and Diagnosis Program Initiative for people diagnosed with breast cancer and their family members. Using your pathology report you are guided step by step through the treatment decision process.



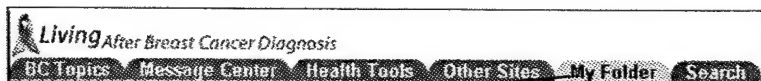
Other Sites

Web Links is a list of good websites that have been selected by CHESS. When you click on one of the links, you will be going outside of the CHESS website. To get back to the CHESS site you can use the BACK button on your browser.

Evaluating Web Info - There is a lot of information on the Web. Some of the information is accurate and

good and worth reading, and some is not. On this website you will find helpful questions and things to keep in mind as you do research on the Web.

Medline is a website maintained by the National Library of Medicine. The site provides a selected list of links to breast cancer resources available on the Web to help you research your health questions.



My Folder

Personal Library allows you to review any documents you saved in it by selecting the "Save in My Personal Library" button.

My Diary provides a place for you to record your personal thoughts, feelings and experiences. This journal is seen only by you. It is not shared with others.

Relief Through Writing is a focused writing exercise that has been shown to improve health by reducing blood pressure, lowering heart rate and improving immune functioning. This exercise is only seen by you. It is not shared with others.

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SEARCHING FOR INFORMATION ON THE WEB

How do I search for a particular topic on the Web?

The best way to find information on the Web is to use a search engine - a site that provides the ability to search for information on the Internet. Search engines are like giant card catalogs available to us (for free!) on the Web. There's been tremendous growth in the number of search engines, but no single source has been able to catalog every single Web page. The total

number of web pages is just too big, growing too rapidly, and with very little organization or control. So a thorough search still may require using more than one search engine.

Another way to search the web is to find a site that has its own search function built into its web site, like the American Cancer Society.

What are some of the more popular search engines?

There are numerous search engines on the Web. Some of the most commonly used are listed below. Each engine works with keywords and phrases, and each engine has a little tutorial.

All in One Search <http://www.allonsearch.com/>
AltaVista <http://www.altavista.com/>
Ask Jeeves <http://www.aj.com/>
Excite <http://www.excite.com/>
Google <http://www.google.com/>

HotBot <http://www.hotbot.com/Infoseek>
Infoseek <http://www.infoseek.go.com/>
Lycos <http://www.lycos.com/>
Magellan <http://magellan.excite.com/>
Webcrawler <http://www.webcrawler.com/>
Yahoo <http://www.yahoo.com/>

Whatever search engine you use be sure to check out its help system for rules, tips and syntax. Almost all search engines use "Boolean logic" which allows you to narrow or broaden your search with terms like AND, OR, NOT or NEAR.

TIP: Add any search engine sites above that you really like to your browser bookmarks/favorites for future use.

How do I perform a search using a search engine?

To perform a search, simply enter one or more keywords into the blank box provided and then click on the Search button. The search engine will look through its catalog of pages and return a list of links to pages that contain at least one of your keywords in either its name or in a special descriptive paragraph which has been submitted to the search engine by the site administrator. A few search engines now claim to search the entire text of each page. Remember computers are literal: they don't understand what they read; they just match on it. So you can get lists of sites that have next to nothing to do with what you're really searching for.

TIPS:

Be sure to try several different search engines when looking for information since each one can have different listings included in its database.

Experiment with putting the words that you are searching for in quotes.

Try narrowing your search down by using the search options menu. For example, at Yahoo, next to the search button, click options. Then try one of the search options such as "an exact phrase match." Also at Yahoo, after you receive your search results, you can then scroll down to the bottom of the page and just click on the other search engines that are listed. You will then get the search results from those search engines.

Are there different types of search engines?

There are basically two types of search engines on the Web: the index, and the directory or subject guide. One way to think of the differences between these two kinds of engines is to think of web sites as books. Indexes catalog every word in every book it looks at, and will list for you each page that contains word(s) you're looking for. Directories and Subject Guides take the overall subject matter of the books it looks at and lists the front covers of the books that match your word(s). The advantage of index search engines is also their disadvantage: they are incredibly inclusive, so if there is a site with the word you're looking for, there is a good chance that these search

engines will find it. The bad news is that you may find far too many sites and you will likely have to sift through a lot to find what you need. Directories and Subject Guides, on the other hand, are less thorough and will often result in a shorter list of search results.

Two popular Index search engines are Alta Vista and Hot Bot. Yahoo and Magellan are examples of Directory/Subject Guide driven search engines. Some search engines use both types of search functions, that is, they are both an index and a directory, like Infoseek and Excite.

Which search engine is the best?

Each search engine has its own way of compiling and collecting information, and therefore each produces different results. To illustrate this point, try using a variety of search engines to look for information on your favorite hobby. You'll see the radically different hits you'll get with each directory and index.

Remember that no one service is perfect, so use as many as you have time for. Using many search engines will also help you get a feel for how the different kinds of services work. You'll soon find yourself using a favorite engine to find all the information you need quickly and painlessly.

How can I perform a search within a single web site?

Really large web sites, like the American Cancer Society, can contain thousands of web pages. This makes even the most well conceived navigation system awkward. A common technique then is to add a search feature to the web site. This allows the reader to enter a few words and the server will construct a page

that has links to relevant pages within the web site. Other sites provide a menu of topics from which to select and perform a search. Either way, remember that these types of searches are performed within a site, not across all Web sites.

Is there a quick way to go to a search engine without having to memorize a URL address?

Here are two quick ways to get to a search engine when you need one:

If you have Netscape Navigator or Internet Explorer, click on your "Search" button on your browser bar at the top of your screen. This will take you to some pre-set search engines.

Make Bookmarks/Favorites of all the search engines, that way if one is very busy you can skip over to the next engine.



CHESS

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<http://chess.chsra.wisc.edu/bcancer>

HOW DO I EXIT CHESS?

DO NOT just shut the computer off. Modern computers must be shut down properly, otherwise they can be damaged.

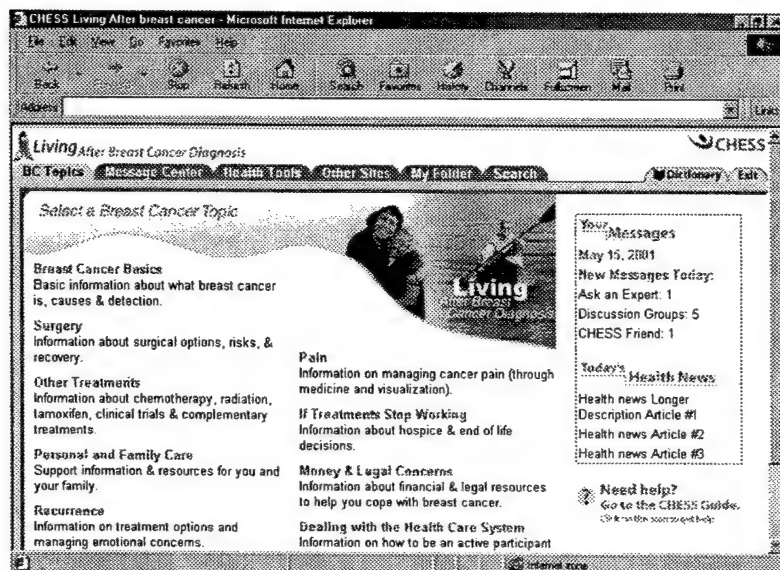


Figure 1

- 1. When you are done, click the "x" in the upper right hand corner of any CHESS screen. (Figure 1)**

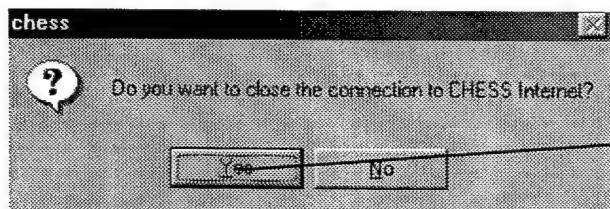


Figure 2

- 2. A box will appear in the middle of your screen that looks like this (Figure 2). To disconnect from the CHESS Internet, click "Yes."**

(If this screen does not appear, call Technical Support at 1-800-480-9223 for help.)

- 3. To turn off your computer, click on the "Start" button on the lower left hand corner of your screen. (Figure 3)**

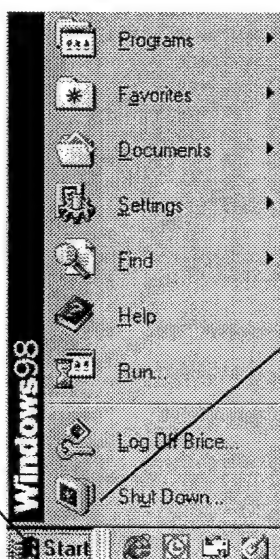


Figure 3

- 4. Then click once on "Shut Down..."**

5. **Another message** will then pop up. (Figure 4)
6. **Make sure "Shut down"** is selected, then click "OK."
7. **When your computer says** "It's now safe to turn off your computer," press the power switch to shut off the computer.

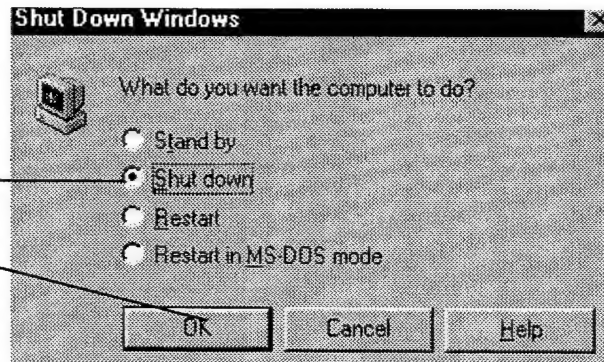


Figure 4

**CHESS**LIVING AFTER BREAST CANCER DIAGNOSIS
<http://chess.chsra.wisc.edu/bcancer>

TROUBLESHOOTING GUIDE FOR INTERNET EXPLORER

What Is The Internet Anyway?

The Internet is basically a large bunch of people using computers that are connected together with telephone lines, cable lines, or via satellite. Computers from other continents are connected to North America by large fiber optic communication lines that run along the ocean floor. Nobody knows how many computers make up the Internet. But the best guess is that there are some thirty to thirty-eight million people that are on-line. New computers and people are constantly being added to the Internet.

No individual, no corporation and no government owns the Internet - it is owned, operated and maintained jointly by all of those who use it, (including you!). Because of this, there are a number of things that can happen as the Internet operates. People make mistakes, computers break down, and phone lines get overloaded or broken. When this happens, you may get an error message indicating that something is wrong. But, it is usually temporary and can be easily dealt with.

What If I Have Problems With Connecting To The Internet?

In order to connect to the Internet, your computer needs to use your phone. If, however, your computer refuses to dial your phone or it dials the phone, but says "Authentication" and asks you for a username and password, it is NOT asking for your CHESS codename

and password. This message merely indicates that your computer has forgotten some information. If this happens to you, call the CHESS help line at 1-800-480-9223 to get instructions on how to enter that information back into your computer.

What Do I Do When I Get An Error Message?

These error messages are just the computer's way of telling you that there is something wrong with the Internet. Most of the time, you can just wait a few

minutes for someone to fix the problem and try again. So, the first things you want to try when you get an error message are the following:

Wait a few seconds and then click on your "Refresh" button. (Located on the upper middle part of your screen)



If the problem is not fixed within a few minutes, then click the "Back" button to go back to the previous page. You can always come back later and see if the problem has been fixed. (Located on the upper left part of your screen)



What Do the Error Messages Mean?

The following chart contains some of the more common error messages and their causes. If you encounter one of these errors while using CHESS and

cannot clear it by using the steps outlined in the chart, call the CHESS help line at 1-800-480-9223 for assistance.

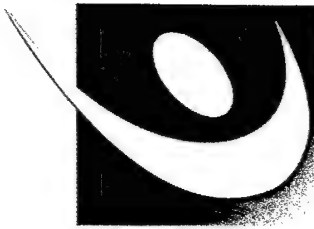
TROUBLESHOOTING GUIDE FOR INTERNET EXPLORER (continued)

Error Message	Cause	Solution
"Authentication" Computer is asking for a user name and password.	Your computer has lost some information that it needs to proceed.	Click the "Cancel" button. Then call the CHESS help line at 1-800-480-9223 for instructions on how to enter that information back into your computer.
404 Not Found	The browser could not find the specific document that you requested from the Internet. The document may have been removed, had its name changed, or have been moved to a new location. This is a problem at the other end and has nothing to do with your computer.	To return to your previous page, click on the Back button.
403 Forbidden/Access Denied	The website you requested requires special permission in order to access it (maybe a password).	To return to your previous page, click on the Back button.
503 Service Unavailable	The host computer is too busy. Try viewing the page again after about 30 seconds.	You can try again by clicking on the Refresh button. To return to your previous page, click on the Back button.
Internet Explorer Script Error Do you want to continue running scripts on this page?	The document you are trying to view has an error in it or the document was garbled. This usually has nothing to do with your computer.	Click on the "Yes" button to continue. You may have to do this several times.
Bad File Request	The document you are trying view has an error in it. This is a problem at the other end and has nothing to do with your computer.	To return to your previous page, hit the Back button.
Cannot Add Form Submission Result to Bookmark List	The results of a form that requires you to enter information (such as a search) cannot be saved as a bookmark. A bookmark can only be a document or an address.	To return to your previous page, click the OK button.
Warning: Page has Expired	The page you requested was created using information you typed into your computer. As a privacy precaution, Internet Explorer does not automatically resend your information to the other computer.	You must explicitly tell Internet Explorer to resend your information and view this Web page. To resend the information, click the Refresh button.
Connection Refused by Host	The website you requested requires special permission to access it. Unless you have this permission, you will not be able to view the site.	To return to your previous page, hit the Back button.

TROUBLESHOOTING GUIDE FOR INTERNET EXPLORER (continued)

Error Message	Cause	Solution
Failed DNS Lookup	This can be caused by a misspelling in the Internet address. Or, it can also be caused by too many people trying to look at a website at once. Perhaps you might try again in 30 seconds.	To return to your previous page, click the Back button.
Connection with the server could not be established	This usually means that the Internet address is wrong in some way. Or, the address may not exist at all. This can also be caused by too many people trying to look at the website at once. Perhaps you might try again in 30 seconds.	Click on the OK button to proceed. You may need to use the Back button to return to your previous page.
File Contains no Data	The browser found the site, but the file is blank. This is a problem at the other end and has nothing to do with your computer.	To return to your previous page, click the Back button.
Helper Application not Found	This error occurs when you try to download a file that needs to use a special program to run. If you don't have the special program on your computer, you will get this error. Examples of the type of files that need helper applications would be sound or video files.	Click on the OK button to proceed. You will not be able to run these files.
Not Found	The link no longer exists. This is a problem at the other end and has nothing to do with your computer.	Click on the OK button to proceed
Site Unavailable	Too many users are trying to access the site, the site is down for maintenance, there is noise on the line, or the site no longer exists. This can also be caused by typing in the wrong Internet address.	Click on the OK button to proceed. You may need to use the Back button to return to your previous page.
TCP Error Encountered While Sending Request to Server	This error is caused by erroneous data on the line between you and the requested site. This may be a problem with your computer or phone line.	Click the OK button to proceed. You may need to use the Back button to return to your previous page. If the problem persists, report the error to the CHES help line at 1-800-480-9223.
Too Many Users	The site is busy. You may want to try again after about 30 seconds.	Click the OK button to proceed. You may need to use the Back button to return to your previous page.
Unable to Locate Host	Your request did not return anything, the site is unavailable, or the Internet connection was dropped. This is usually a problem at the other end and has nothing to do with your computer.	Click on the OK button to proceed. But, if you get this message all the time, you should call the CHES help line at 1-800-480-9223.

Appendix 5:
Internet User Manual



CHES

Comprehensive Health
Enhancement Support System

BASIC WEB SKILLS

INFORMATION AND TIPS ABOUT THE INTERNET AND HOW TO USE IT

TECHNICAL SUPPORT: 1-800-480-9223
Mon.-Fri. 8:30 am-4:00 pm, Central Time

GENERAL HELP: 1-800-361-5481

Below is a list of several Websites, the Web address (or URL), and a brief description of the site:

Name of Website: Breast Cancer Network

Web Address: <http://www2.cancer.org/bcn/index.html>

Site description:

The Breast Cancer Network provides up to date information about breast cancer including survivorship, advocacy, news, and resources.

Name of Website: Komen.org

Web Address: <http://www.komen.org>

Site description:

This website provides information about education, screening, research and treatment for breast cancer. It targets women with breast cancer, their families and those who support them. It also seeks to education the public about breast cancer and the issues surrounding the disease.

Name of Website: Celebrating Life Foundation

Web Address: <http://www.celebratinglife.org/index.html>

Side description:

This website contains breast cancer information, questions and answers, breast self-examination, stories from breast cancer survivors, and activities and events. This site particularly targets African American women and women of color.

Name of Website: Y-ME National Breast Cancer Organization

Web Address: <http://www.y-me.org>

Site description:

This website provides information about breast cancer and resources to turn to for support and further assistance. Services include Frequently Asked Questions (FAQ), Survivor Stories, Y-ME Newsletter, Y-ME Publications, Question Forum, and Links to other sites.

Name of Website: American Cancer Society

Web Address: <http://www.cancer.org>

Site description:

Provides information on American Cancer Society (ACS) programs and events and local ACS Chapters as well as comprehensive information about diagnosis and treatment.

Name of Website: OncoLink

Web Address: <http://oncolink.upenn.edu/>

Site description:

OncoLink is affiliated with the University of Pennsylvania Cancer Center. OncoLink provides information on many types of cancer. Some of the areas covered include Frequently Asked Questions and Answers about Cancer (FAQ), Cancer Causes, Screening and Prevention, Clinical Trials, and Global Resources for Cancer Information.

How Do I Use a Mouse?

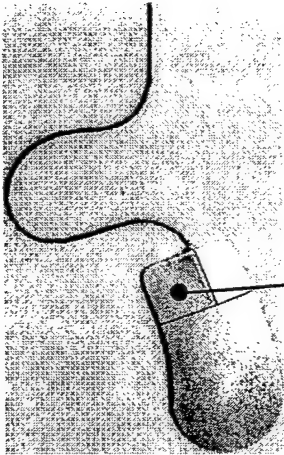


Figure 1

A mouse (Figure 1) is used to point to and click on items like buttons, hyperlinks or scroll bars on your computer screen. (To find out more about hyperlinks and scroll bars, see "What Do I Need to Know About the Screen?") Clicking on these items allows you to move from one place to another through the CHESS system.

To hold a mouse, place your hand lightly on top of it. If you are right-handed, position your index (pointer) finger on the left button and your middle finger on the right button. (The reverse if you are left-handed).

The **left button** will be the one you click on. *You will never have to click the right button when using CHESS.*

Move the mouse across a flat surface. As you move it, notice the cursor (either a small arrow or a "I" on the computer screen moves the same direction.

Clicking on a Hyperlink or Button

To click on a hyperlink or button, move the mouse till the cursor on your screen touches the hyperlink or button you want. Depending on what you are pointing at, the cursor may change to a small arrow or hand. Click once with your left mouse button. This will take you to the related pages.

Clicking on the Scroll Bar

To scroll (move) the page up or down on the screen, move the mouse till the cursor touches the scrollbar. (Figure 2) There are two ways to scroll.

1. Using the up or down arrows

- Position the cursor on the arrow above or below the grey bar.
- Click the left mouse button. This will make the move the page up or down, depending on which arrow you click on. For example, to see the top of the page, click on the up arrow.

2. Using the sliding bar

- Position the cursor on the darker grey bar.
- Press and hold the mouse button, and drag the bar in the direction you want the page to scroll (e.g. to see the bottom of the page, pull the bar downwards).

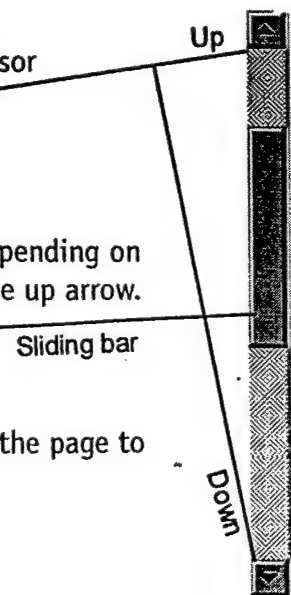
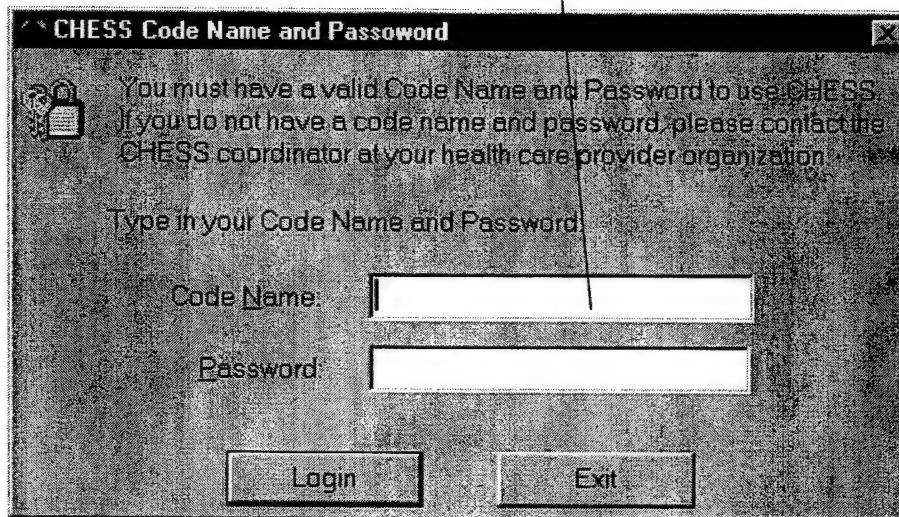


Figure 2

How Do I Start?

After you double-click on the CHESS icon on your desktop, you will be asked for your CHESS code name and password (Figure 1). Type those in the spaces provided.

A screenshot of a Windows-style dialog box titled "CHESS Code Name and Password". The dialog has a dark background with a lighter central area. At the top left is a small icon of a padlock with a question mark. To the right of the icon, the text reads: "You must have a valid Code Name and Password to use CHESS. If you do not have a code name and password, please contact the CHESS coordinator at your health care provider organization." Below this text is the instruction "Type in your Code Name and Password". There are two input fields: the first is labeled "Code Name:" and the second is labeled "Password:". At the bottom of the dialog are two buttons: "Login" and "Exit".

CHESS Code Name and Password

You must have a valid Code Name and Password to use CHESS. If you do not have a code name and password, please contact the CHESS coordinator at your health care provider organization.

Type in your Code Name and Password

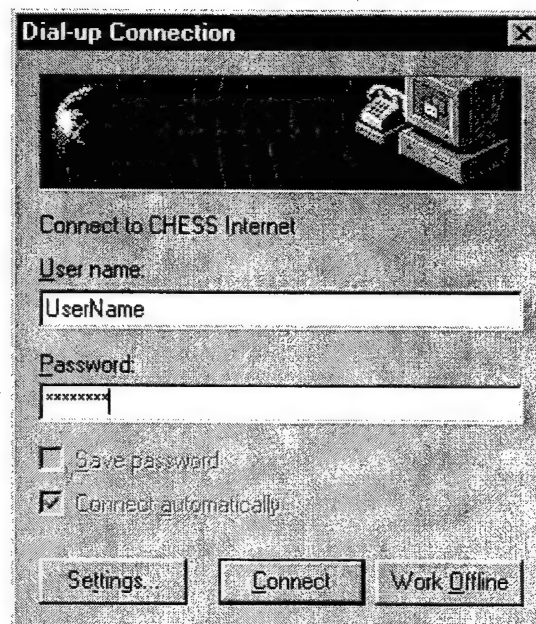
Code Name:

Password:

Login Exit

Figure 1

Once you click the "Login" button, the computer will dial your phone to connect to the Internet. While it is connecting, you will see this message (Figure 2). The computer should connect automatically, so you should not have to click on any buttons just yet.

A screenshot of a Windows-style dialog box titled "Dial-up Connection". The dialog has a dark background with a lighter central area. At the top left is a small icon of a globe. To the right of the icon is a small illustration of a computer monitor and a telephone. Below the icons, the text reads: "Connect to CHESS Internet". There are two input fields: the first is labeled "User name:" and the second is labeled "Password:". Below the password field is a checkbox labeled "Save password" and another checkbox labeled "Connect automatically". At the bottom of the dialog are three buttons: "Settings...", "Connect", and "Work Offline".

Dial-up Connection

Connect to CHESS Internet

User name:

Password:

☐ Save password

☒ Connect automatically

Settings... Connect Work Offline

Figure 2

On rare occasions the computer might forget your Dial-up User Name and Password. If this happens, you will see a screen that indicates you entered an "invalid user name or password" (Figure 3.) Just type them in again and the computer should remember them. If you experience any problems with this, call the CHESS help line at 1-800-480-9223

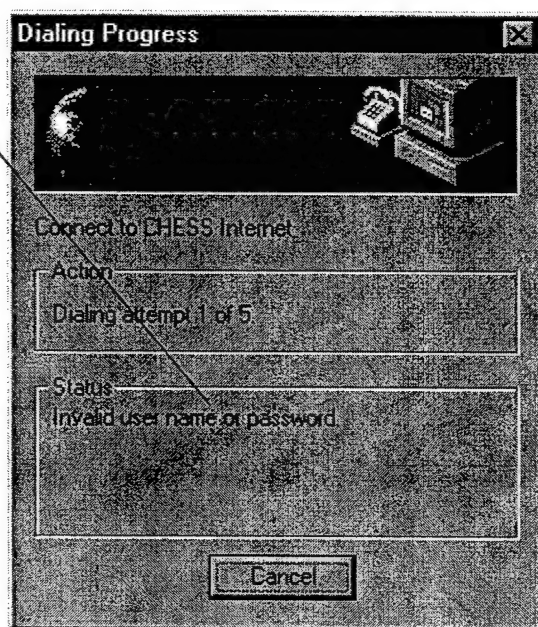


Figure 3

----- Cut Here -----

Keep these in a safe place: Your Username is _____

Your Password is _____

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Where can I go for more advanced instruction on how to use the Internet?	

BASIC WEB SKILLS INFORMATION

Welcome! This section reviews the basics of searching the World Wide Web. The information and tips provided here are designed for people who are new to the Internet and perhaps even new to personal computers. Here, you will learn the basic skills and information you need to get going on the Web and, with a little practice, you'll quickly pick up the rest.

As you begin to use the Internet, you may be confused or overwhelmed by the sheer volume of information, entertainment, and really bad design that's out there. Don't let it intimidate you; the Internet is really just another form of library, and like a library, there is a way to find the information it contains. Think of the Internet as a new information-seeking tool.

Remember to relax and have some fun with this technology. Before you know it, you'll be using it like a pro!

THE INTERNET DEFINED

What is the Internet?

The Internet (also known as cyberspace, the Information Superhighway, and the Net) is a global network of computers linked together to send and receive information. The computers are joined through high-speed connections using satellites, cables, and phone lines. All these computers are considered part of the Internet because they speak a common language -- or protocol (called the Transmission Control Protocol / Internet Protocol -- or TCP/IP). TCP/IP is what makes it possible for your personal computer to communicate with another computer on the other side of the world.

Where did the Internet come from?

The Internet evolved from a Defense Department project in the late 1960s to link military researchers at four universities. It was designed as a decentralized network so that it couldn't be knocked out by a single nuclear attack. During the 1980s, the Internet was adopted by the National Science Foundation that provided funding to make it available to a wider array of scientists and researchers. Later it was opened up for commercial use. The Internet is now an international network of at least 60,000 smaller, independent computer networks.

Who's in charge of the Internet?

The simple answer is that there is no one group that is in charge of the Internet, although a number of companies have played major roles in putting the framework together (CompuServe, America Online, Microsoft, MCI and Netscape, to name a few). There are also several international organizations that are concerned with creating technical standards and discussing the Web's programming languages.

But in large part, the Internet is actually run by local computer administrators who are responsible for maintaining the individual computers that are part of the larger network of computers that forms the Internet. The person running an Internet site computer system is called a **Webmaster** or **Web Manager**.

So, if you object to material located on a certain Internet site, the person you could contact would be that site's Webmaster. Or, say you are having connection problems; the person you should call would be the company supplying your connection.

GETTING ONLINE

How do I hook up to the Internet?

To hook up to the Internet, you simply connect your personal computer to one of the computers that is part of the Internet. To connect your computer to another computer, you use an Internet Service Provider or ISP. Once you are online (connected to another computer via your phone line), your computer can talk to any other computer on the Internet, whether its in your hometown or on the other side of the world.

Am I charged for a long distance phone call when I connect to a web site in another state or country?

No, you pay only for the local telephone call* that connects your computer to a computer that is hooked into the Internet. At this time, the Web transfers information using computer lines and other non-telephone connections, so long distance charges are not incurred. The only other charge that you may incur is the subscription fee for an Internet Service Provider (ISP) or an Online Service.

*** Exception:** Internet users in rural areas may have to pay a long distance fee if their ISP is not within their local telephone billing area.

What are Internet Service Providers (ISPs) and Online Services?

ISPs and online services are commercial services that provide a gateway between your computer and the Internet. The distinctions between the two are starting to blur, but generally, ISPs simply provide a connection to the Internet, and online services provide a connection to the Internet as well as special services available only to their subscribers. Some major online services include America Online, CompuServe, Microsoft Network, and Prodigy.

Generally, ISP and Online Service subscribers pay a monthly membership fee (about \$10-\$20) in addition to a per hour charge after the first few hours. This fee covers the costs of buying and maintaining the expensive computers and leased lines that are necessary to hook into the Internet. Check around to see what is the best deal for you. Not all ISPs are the same.

Note that some businesses and schools provide connections to the Internet for their employees and students. If your work or school provides Internet access, you won't need to pay for an ISP or Online Service.

What are web servers and clients?

Simply put, the Internet is a lot of computers that are linked together. When you go online, your computer is linking (via your phone line) to a computer. You can't link to any old computer though; you have to link to a computer that allows external access by other computers and has the right software to process requests for files or web pages. This kind of computer is called a **web server**. A web server is a computer that stores web pages and makes them available for outside access. A web server sends files across the network where your computer receives and interprets them.

When you're online, your computer is the **client**. When you tell your computer to bring you to your homepage, your client communicates with the web server where the files are located. It's important to understand that navigating the Internet involves nothing more than telling a computer where to find the file you'd like.

A web server is generally hooked up 24-hours a day, ready to serve your needs. When it receives a request, it responds by sending the requested file. A web server may get only a few requests in a day or it may get millions. Each request it gets is called a **hit**.

WEBSITE STUFF

What is a web page?

A **web page** is a single file that can be displayed on the Web. Some web pages are just a few lines of text and others have as much text as several book pages. Here's the key: if you can get to all the information by just scrolling (moving up and down in the page by clicking on the triangle arrows on the right side of your screen), it's all one web page. If you have to "click here" or use your mouse to select additional information, you've gone to a new web page -- which may or may not be at the same web site. Web pages can be made up of writing, pictures, sound, animation and video.

What is a web site?

A **web site** is a collection of one or more web pages linked for a common purpose with a common theme. A web site may have a single page -- or it may have thousands -- or anywhere in between. Web sites are often contained at a single physical location, reside on a single server computer, and may have a single author or multiple authors.

How are web pages and web sites created?

Web pages are created using a computer language called the Hyper Text Markup Language (HTML). This may sound complicated but it really isn't. HTML is basically instructions telling your computer how to display text and graphics and how to link to other sites.

MOVING AROUND THE INTERNET

What is a Web Browser and which one do I have?

A **browser** (also called a **client**) is a type of software that enables you to search the Web and display web pages. Browsers can also help you transfer files, and send and read electronic mail. Your browser starts once you connect to the Internet.

The two most widely used browser programs are **Netscape Navigator** and Microsoft's **Internet Explorer**. Every year these programs are improved and newer versions are released. To check to see which browser version you have, click on the Help Menu on the bar at the very top of your screen, and then select "About Netscape" or "About Internet Explorer." This will display a window showing which version you have.

What is a hyperlink and how can I spot one?

Hyperlinks (or **links**) are hidden instructions buried in a web page that make it possible for you to jump (or "navigate") from place to place on the Web. When you click on a link, the instructions tell your computer to display a connected web page. Clicking on a link can take you to another place on the same web page, to another page in the same site, or to another site altogether.

So what does a link look like? Links can be text, a picture, or an image. They can be anywhere on a page, and sometimes they are almost invisible. There is one sure way to check to see if something is linked: place your mouse pointer over the text or image. If your pointer turns into a little hand with one finger extended, you are on a link. To activate the link, just click, and you will be instantly transported to another web page that has been connected with the current page.

Every time you click on highlighted text to go to another page on the Web, you're following a link. **Text links** (also called **hypertext**) are usually underlined and of a different color (the standard color is blue). **Graphical links** (pictures or images) are often accompanied by instructions (for example, "click here to continue"), and sometimes have borders.

Links have good and bad points. Links can take you to interesting and relevant sites, and can make research fast and easy. Without links, you'd be stuck on the same web page forever! However, one drawback to links is that they can take you further and further from your original web site. Also, they

are not necessarily an efficient way to find specific information since you don't really know where you're going until you get there, and several clicks in you may not remember just how to get back to an earlier item.

Is there something wrong with my computer when I click on a link and nothing happens?

Probably not. Just like your local freeways at rush hour, the Internet gets traffic jams at times. The best way out is to click on the "Stop" button in your browser bar at the top of your screen, and then try clicking on the link again. If it is still taking a long time, try waiting a few minutes for things to settle down. This often clears things up. The problem is usually with the computer you are trying to connect to, not your computer.

How can I move from one web page to another web page?

At the top of your browser window, you'll see a bar with buttons. These buttons will help you get around the web. There are a four key ways to move around on the Web:

1. Type in the address of the web site you would like to visit.
2. Use your **Forward and Back buttons** on your browser's toolbar.
3. Use your **Go** function to select previously visited sites from your current browsing session.
4. Bookmark the web site for future access.

What is an URL?

URL (pronounced "earl" or spelled out as U.R.L.) stands for **Uniform Resource Locator**, but you certainly don't need to remember that! What you do need to know is that an URL is a web page's address on the Internet. Every document or resource on the Internet has a unique URL. The URL tells the software running the Internet where the page you want is located so it can be retrieved and sent to your computer.

Just like a postal address, which requires a street address, city, state and zip, a URL requires certain parts necessary to distinguish it from all other web pages.

What are the different parts of an URL (web address)?

Each web address (URL) can be broken into three parts. Reading an address from left to right they are the **protocol** (such as http://, ftp://, gopher://); the **server** or **domain name** (everything before the

first single forward slash); and the **file path** and **filename** (everything after and including the first single forward slash).

Let's take, for example, the address <http://www2.cancer.org/contact/> (the address for the American Cancer Society's Contact Page on their Website). It may look ridiculously complicated, but we'll make some sense of it. First of all, a period is always called a "dot". A "dot" separates major parts of the address, a "slash" separates subdivisions of the main parts. A "dash" is used to connect words, since spaces are not allowed in a URL. Let's break this URL down:

http://

This part tells the computer what type of protocol (or computer language) to use to read the web page. Http stands for "Hyper Text Transfer Protocol." It's the same for virtually every page so you really don't need to be concerned with it. You probably don't even need to include "http" in typing in an URL because your browser assumes that you're looking for an "http" page.

www2.cancer.

This is called the domain name - the registered name of the computer holding the web page and the directory. Note that the domain name is followed by another "dot".

org/

Next you'll see a code which identifies the type of domain site (who owns and operates the web site). There are seven basic types:

- com - commercial
- edu - educational institution
- gov - governmental body
- int - organizations established by international treaty
- org - nonprofit organization
- mil - military services
- net - Internet gateway or administrative host

Most sites outside the United States use a two-letter code which identifies the country rather than one of the three-letter codes above, such as "au" for Australia or "fr" for France.

Contact/

This is the final part of the URL. It tells your computer the name of the file that makes up the page.

How can I visit a web site whose address (URL) I already know?

If you know the web address of the site you want to visit, you can enter it one of two ways:

1. Type the URL directly into the **Address** or **Location** line (at the top of your browser window, below the Back button), then hit the **Enter key** on your keyboard.
2. From the browser bar at the top of your page, click on File. From the pull-down menu, select **Open** or **Open Page**, and type the URL into the box that appears.

How do I use the Back and Forward buttons?

At the top of your Browser, the very top left-hand button is marked **Back** and/or has a little arrow pointing to the left and the button next to it is marked **Forward** and/or has a little arrow pointing to the right. With these buttons, you can flip back and forward through web pages you have visited during your current search (in other words, these buttons will display only those web pages you have viewed during your current sitting, not web pages from yesterday or last week).

To use the Back button, simply click on it and you will be returned to the page you were viewing just before the current one. If you see another link that looks interesting on your way, you may choose to follow it. To use the Forward button, simply click on it and you will go to the page you were viewing just after the current one.

Notice that after you've followed a link and then returned to the original page, the color of the link has changed (usually from blue to purple unless the web page designer has chosen other colors for the page). A changed color means that you've already followed that link.

How do I use the Go function?

You can use your Go function to select previously visited sites from your current browsing session. Go is temporary, and will erase when you quit your search session.

To use the Go function in Internet Explorer (notice: there isn't a button labeled "Go"),

1. Next to the Forward and Back Arrow Buttons at the top of your Browser bar, you'll see little triangles that point down. If you put your cursor over the arrow, a list of all the sites you have visited during your current search session will appear. To select a site, simply click on the site of your choice from this list.

To use the Go function in Netscape Navigator,

1. Click on Go menu and look at the list. Go records the web sites you've visited during this Netscape session. Select a location from the Go menu by simply clicking on the web site of your choice.

MARKING YOUR PLACE

What is a browser bookmark (or favorite)?

Perhaps the best way to find sites that you visit regularly is to **bookmark** them. Just like the cardboard ones that you stick into a printed book, a browser bookmark is a placeholder to a particular URL (web address) that you set using your browser software for ready access later.

Netscape Navigator calls this feature **Bookmarks** while Internet Explorer calls it **Favorites**. In both cases, this browser feature allows you to store a list of web pages so you can go back anytime without having to remember and type in the actual URL (web address).

How do I make and revisit a bookmark/favorite?

If you find a web site you'd like to revisit, just click on the word Bookmarks or Favorites at the very top of your screen. A menu will appear with the option to add a Bookmark or Favorite; click on this option to add the current web page URL to your list of Bookmarks/Favorites.

The next time you want to visit that web page, simply click on the site name from same Bookmarks/Favorites menu. To organize or delete web sites from your Bookmarks/Favorites list, look under the Bookmarks/Favorites menu, and select Edit Bookmarks or Organize Favorites. This will open your Bookmarks/Favorites file and you can edit, delete and organize them from there.

USING THE WEB

What does "surfing the Web" mean?

One of the most enjoyable aspects of the Internet is browsing various web sites - or "surfing the Web."

It's a phrase referring to the hopping from place to place on the World Wide Web using hyperlinks. It's

rather like going down to a large bookstore and wandering around according to some strategy. For

example, you might head straight for the sales clerk and ask for a specific book by title or author. Or

you might head for the section of books of interest to you, e.g., sports, travel, cooking, history,

fiction, etc. Perhaps you just start wandering up and down the aisles waiting for something to catch

your attention. Regardless of the strategy you use, you will eventually come across a book that you will

pick up and browse through, maybe reading a paragraph or two, glance at a few pictures, and maybe

even check the table of contents. This brief encounter will enable you to decide whether you should put

the book back, buy it, or carry it around as a possible purchase.

Well, the Internet can be viewed as the greatest bookstore in the world, with web sites much like books

containing pages of text and pictures and even sound and video clips. Once you understand a few

basics to finding and moving around web sites, browsing on the Web can lead to the discovery of other

information. Perhaps you are intent on tracking down a specific piece of information or a person. Or

you maybe you'd like to pick an area of interest and find a listing of web sites with information on that

topic. Once you find a web site of interest and check out a few pages, you might decide to bookmark

the web page so you can easily return later. You could spend a couple of hours reading, looking at

pictures, browsing over the comments in an online forum, chatting live online with others with similar

interests, or sending an e-mail inquiry about a topic, product, or person.

Surfing the Internet, like browsing a bookstore, can be a fun and productive experience. It can also be

rather tiring, like the information overload you might experience after a few hours in a bookstore. Many

people spend 1 to 3 hours surfing in the evening or on the weekend as a leisure activity. If you want to

broaden your horizons and knowledge, surfing the net is a great way to do it.

SEARCHING FOR INFORMATION

How do I search for a particular topic on the Web?

The best way to find information on the Web is to use a **search engine** - a site that provides the ability to search for information on the Internet. Search engines are like giant card catalogs available to us (for free!) on the Web. There's been tremendous growth in the number of search engines, but no single source has been able to catalog every single Web page. The total number of web pages is just too big, growing too rapidly, and with very little organization or control. So a thorough search still may require using more than one search engine.

Another way to search the web is to find a site that has its own search function built into its web site, like the American Cancer Society.

What are some of the more popular search engines?

There are numerous search engines on the Web. Some of the most commonly used are listed below.

Each engine works with keywords and phrases, and each engine has a little tutorial.

All in One Search	http://www.allonesearch.com/
AltaVista	http://www.altavista.com/
Ask Jeeves	http://www.aj.com/
Excite	http://www.excite.com/
HotBot	http://www.hotbot.com/Infoseek
Infoseek	http://www.infoseek.go.com/
Lycos	http://www.lycos.com/
Magellan	http://magellan.excite.com/
Webcrawler	http://www.webcrawler.com/
Yahoo	http://www.yahoo.com/

Whatever search engine you use be sure to check out its help system for rules, tips and syntax. Almost all search engines use "Boolean logic" which allows you to narrow or broaden your search with terms like AND, OR, NOT or NEAR.

TIP: Add any search engine sites above that you really like to your browser bookmarks/favorites for future use!

How do I perform a search using a search engine?

To perform a search, simply enter one or more keywords into the blank box provided and then click on the Search button. The search engine will look through its catalog of pages and return a list of links to pages that contain at least one of your keywords in either its name or in a special descriptive paragraph which has been submitted to the search engine by the site administrator. A few search engines now claim to search the entire text of each page. Remember computers are literal: they don't understand what they read; they just match on it. So you can get lists of sites that have next to nothing to do with what you're really searching for.

TIPS:

1. Be sure to try several different search engines when looking for information since each one can have different listings included in its database.
2. Experiment with putting the words that you are searching for in quotes.
3. Try narrowing your search down by using the search options menu. For example, at Yahoo, next to the search button, click options. Then try one of the search options such as "an exact phrase match." Also at Yahoo, after you receive your search results, you can then scroll down to the bottom of the page and just click on the other search engines that are listed. You will then get the search results from those search engines.

Are there different types of search engines?

There are basically two types of search engines on the Web: the index, and the directory or subject guide. One way to think of the differences between these two kinds of engines is to think of web sites as books. Indexes catalog every word in every book it looks at, and will list for you each page that contains word(s) you're looking for. Directories and Subject Guides take the overall subject matter of the books it looks at and lists the front covers of the books that match your word(s). The advantage of index search engines is also their disadvantage: they are incredibly inclusive; so if there is a site with the word you're looking for, there is a good chance that these search engines will find it. The bad news is that you may find far too many sites and you will likely have to sift through a lot to find what you are looking for. Directories and Subject Guides, on the other hand, are less thorough and will often result in a shorter list of search results.

Two popular Index search engines are Alta Vista and Hot Bot. Yahoo and Magellan are examples of Directory/Subject Guide driven search engines. Some search engines use both types of search functions, that is, they are both an index and a directory, like Infoseek and Excite.

Which search engine is the best?

Each search engine has its own way of compiling and collecting information, and therefore each produces different results. To illustrate this point, try using a variety of search engines to look for information on your favorite hobby. You'll see the radically different hits you'll get with each directory and index.

Remember that no one service is perfect, so use as many as you have time for. Using many search engines will also help you get a feel for how the different kinds of services work. You'll soon find yourself using a favorite engine to find all the information you need quickly and painlessly.

How can I perform a search within a single web site?

Really large web sites, like the American Cancer Society, can contain thousands of web pages. This makes even the most well conceived navigation system awkward. A common technique then is to add a search feature to the web site. This allows the reader to enter a few words and the server will construct a page that has links to relevant pages within the web site. Other sites provide a menu of topics from which to select and perform a search. Either way, remember that these types of searches are performed within a site, not across all Web sites.

Is there a quick way to go to a search engine without having to memorize a URL address?

Here are two quick ways to get to a search engine when you need one:

1. If you have Netscape Navigator or Internet Explorer, click on your "Search" button on your browser bar at the top of your screen. This will take you to some pre-set search engines.
2. Make Bookmarks/Favorites of all the search engines, that way if one is very busy you can skip over to the next engine.

MISCELLANEOUS INFORMATION

What does it mean when I click on a link and get a "File Not Found" message?

This error message indicates that your computer was unable to locate a web page at that particular URL (web address). Some common reasons for this error message are:

- the web page's URL was changed
- web page's URL was incorrectly listed by the linked page
- the web page no longer exists
- the server holding this URL is temporarily out of commission

Remember that the Internet is in a state of constant change. Web sites come and go, many sites relocate without telling anyone, and dead listings are everywhere. Remember to use more than one search engine when trying to find a page that may have been moved.

How can I see more of a web page on my screen?

If the window in which you're viewing a web page is not expanded to the full width of the screen, you may want to "maximize the window." This way the designed pages will fill the entire width of the screen, and you will have less scrolling down to do as you read. Here's how:

For Windows:

Click on the middle box in the upper right hand corner of your screen. If the window is not maximized, the icon looks like a single window frame. After you click on it to maximize, it will change to two smaller frames, one in front of the other.

For a Macintosh:

Click on the box located in the upper right corner of the window (with a right angle in it).

In all cases, clicking on the same box will return the window to its original size. If the maximize button does not resize the window to fill the entire screen, there is a sizing handle in the lower right hand corner of the window. If you click and hold your mouse on this corner, you can drag the window to whatever width you desire.

Should I be concerned about my privacy on the Internet?

Like the real world, aspects of the Internet can pose danger and harm. And, like the real world, there are precautions you can take to protect yourself. The main thing to be aware of is that Internet sites may use or give to others any information you provide, without your permission.

Below are some tips to help you protect your privacy, anonymity and security on the Internet:

1. Never give personal information (such as your name, age, gender, address, or phone number) in e-mail messages, chat rooms, bulletin boards, newsgroups or listservers. Choose a screen name that does not reveal your identity, gender or location. Explore the privacy protections available through your Internet Service Provider (ISP).
2. Before giving financial information (such as your bank account or credit card number) to an on-line company, make certain that the Web site is authentic and that you understand their privacy, customer-service and refund policies. Reliable sites will provide an encryption system to protect your account security.
3. Protect your online password(s). Never tell your password to anyone online. No reliable company or service technician will ask for it. Many people change their passwords regularly. It's an easy way to protect your privacy online, particularly if you think someone has discovered or is using your current password.
4. Before submitting surveys and registration forms on the Internet, be sure you know why the site is collecting the information and what they are going to do with it.
5. Read the privacy policy of any site you visit.
6. Never give details about your plans to be out of the house or traveling to anyone.
7. Report any X-rated, threatening or hostile mail to your Internet Service Provider.

Where can I go for more advanced instruction on how to use the Internet?

For more advanced, step-by-step guides to exploring the Internet, using email, downloading files, participating in online chat rooms, and using bulletin boards, check out the following sites:

<http://www.newbie-u.com/>

<http://www.webnovice.com/faq.htm>

<http://www.larrysworld.com/primer.htm>

<http://www.learnthenet.com/english/index.html>

<http://www.educ.sfu.ca/tutorial/>

How Do I Exit?

1. **DO NOT** just shut the computer off. Modern computers must be shut down properly, otherwise they can be damaged.
2. When you are done, click the "x" in the upper right hand corner of any screen. (Figure 1)

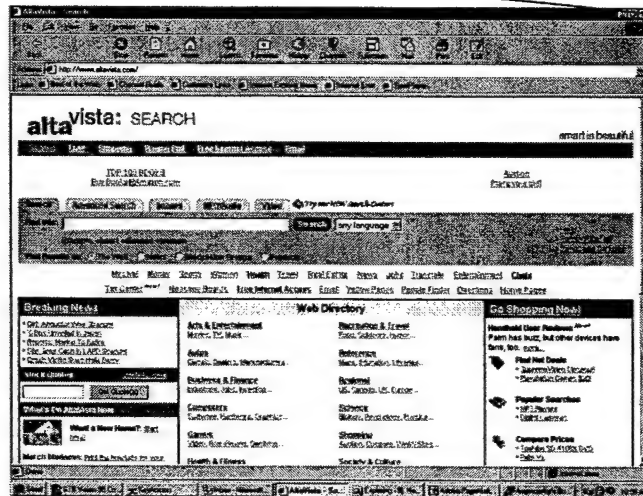


Figure 1

3. To disconnect your computer from the Internet, double-click on the two attached computers down in the bottom right-hand side of your screen (Figure 2).



Figure 2

4. A box will appear in the middle of your screen that looks like this (Figure 3). Click the Disconnect button to disconnect your computer from the Internet.

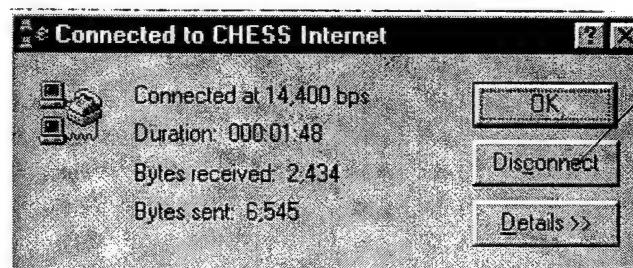


Figure 3

4. To turn off your computer, click on the "Start" button on the lower left hand corner of your screen. (Figure 4)
5. Then click once on "Shut Down..."

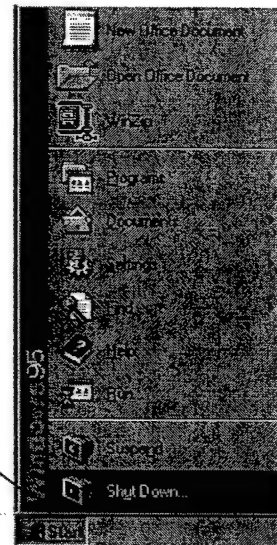


Figure 4

6. Another message will then pop up. (Figure 5)
7. Choose "Yes".

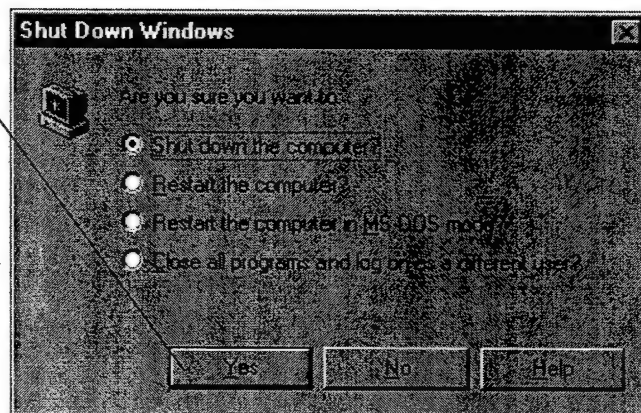


Figure 5

8. When your computer says *"It's now safe to turn off your computer"*, press the power switch to shut off the computer.

Appendix 6:

Pretest Survey.

CHES Project:

Comprehensive Health Enhancement Support System

PreTest

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

For this research on different kinds of assistance for women facing breast cancer, we need to have some idea how you're doing now, before the study starts. Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

<i>At this time...</i>	Not at all	A little bit	Some- what	Quite a bit	Very much
1. There are people I could count on for emotional support.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. There are people I could rely on when I need help doing something.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. There are people who will help me evaluate things I'm finding out about my illness.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. I am pretty much all alone.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. There are people who can help me find out the answers to my questions.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. There are people who will fill in for me if I am unable to do something.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Below is a list of statements concerning how you're dealing with breast cancer. By checking one box per line, please indicate how much you agree/disagree with each statement during the past 7 days. [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither agree or disagree	Agree	Agree very much
7. I needed more information about breast cancer from the perspective of patients who have been there.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. I needed more understandable information about breast cancer.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I needed more information about the latest breast cancer research.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. I needed more contact with people who understood what I was going through.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11. I needed help making decisions.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
12. I understood what my doctor told me.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
13. I was confident I could have a positive effect on my health.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
14. I set some definite goals to improve my health.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
15. I was generally able to accomplish my goals with respect to my health.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
16. I actively worked to improve my health.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
17. I felt that I was in control of how and what I learned about my health.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

At this time...

	Not at all	A little bit	Some-what	Quite a bit	Very much
18. I am able to work (including work in home).	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
19. My work (including work in home) is fulfilling.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
20. I am able to enjoy life "in the moment".	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
21. I am sleeping well.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
22. I am enjoying my usual leisure pursuits.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
23. I feel sad.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
24. I feel like my life is a failure.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
25. I feel nervous.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
26. I am worried about dying.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
27. I feel like everything is an effort.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
28. I am worried that my condition will get worse.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Please indicate how true each statement is for you. [CHECK ONE BOX ON EACH LINE]

During the past 7 days:

	Does not apply	Not at all	A little bit	Some-what	Quite a bit	Very much
29. I was short of breath.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
30. I was self-conscious about the way I dress.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
31. I was bothered by swollen or tender arms.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
32. I felt sexually attractive.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
33. I worried about the risk of cancer in other family members.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
34. I worried about the effect of stress on my illness.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
35. My change in weight bothered me.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
36. I was able to feel like a woman.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Thinking about your experiences since you've had breast cancer, how much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
<i>Since I've had breast cancer,</i>					
37. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
38. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
39. I feel comfortable in asking the physician or nurse questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
40. I feel confident in making decisions about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
41. I can figure out how and where to get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
42. I know what questions to ask my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
43. I am able to be assertive with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
44. I have confidence in my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

How much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
<i>At this point I feel I understand:</i>					
45. The effect my treatment will have on my quality of life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
46. How to deal with breast cancer in my work and with my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
47. What my treatments will be like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
48. The Pro's and Con's of various treatment approaches.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
49. How to know if a health care provider is good.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
50. How to get through my treatments and their side effects.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
51. How to get a second opinion if I want one.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please tell us about yourself BEFORE you were diagnosed with breast cancer (even before you first noticed the symptom or had the test that raised the possibility of breast cancer). Try to remember how you were feeling then in answering the following question. . [CHECK ONE BOX]

52. In general, would you say you have been:

☐1 Feeling normal with no complaints and able to carry on your usual activities.

☐2 Performing normal activities with some effort and minor signs of illness.

☐3 Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime.

☐4 Disabled, requiring special care and assistance in most activities & in bed more than 50% of the daytime, but not all day.

☐5 Very sick, hospitalized for some time or in bed all of the time.

Appendix 7:

2,4,6 Week Survey

CHES Project:

Comprehensive Health Enhancement Support System

2-Week Post Test

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number:_____

TREATMENT DECISIONS

1. *Check the box that best describes how you would like to make important treatment decisions:*
[CHECK ONLY ONE BOX]

- ☐₁ I prefer to make the decision about my treatment myself
- ☐₂ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion
- ☐₃ I prefer that my doctor & I share responsibility for deciding which treatment is best for me.
- ☐₄ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.
- ☐₅ I prefer to leave all decisions regarding treatment to my doctor.

2. *Please indicate if, during the last two weeks, you have considered whether or not to have any of the following treatments.*

In the last 2 weeks I considered... [CHECK ALL THAT APPLY]

- ☐₁ Fine needle biopsy
- ☐₂ Lumpectomy versus mastectomy
- ☐₃ What to radiate (e.g., axillary or underarm lymph nodes)
- ☐₄ Breast reconstruction
- ☐₅ Type of reconstruction
- ☐₆ Timing of reconstruction
- ☐₇ Lymph node sampling
- ☐₈ How many lymph nodes to sample
- ☐₉ Chemotherapy
- ☐₁₀ Type of chemotherapy
- ☐₁₁ Length of chemotherapy
- ☐₁₂ Bone marrow transplant
- ☐₁₃ Oophorectomy (ovary removal)
- ☐₁₄ Tamoxifen
- ☐₁₅ Clinical trial participation
- ☐₁₆ Immunotherapy
- ☐₁₇ Alternative treatments
- ☐₁₈ Stopping treatment
- ☐₁₉ Other, please specify: _____

3. *Of the decisions that you checked above, what one was the most important to you?*

If you did **not** check any of the decisions above, check here ☐ and go to the top of page 3.

Thinking about the most important treatment decision you considered, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX PER LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult to make a choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. It's clear what choice is best for me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. I'm aware of the choices I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I know the relative benefits of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I know the relative risks and side effects of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. The information I have to make this decision is easy to understand.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. I have no problem using the information I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Consulting someone else would have been useful in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. I am satisfied that I am adequately informed about the issues important to my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. I need more advice and information about my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. I have access to information on all my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

If you have decided what to do for this decision at this point, please indicate how much you agree/disagree with the following statements. Otherwise please go to the beginning of page 3.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My treatment choice is sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. I am satisfied with my treatment choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My treatment choice is the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I am satisfied that my treatment choice was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I feel I have made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

NON-TREATMENT DECISIONS

1. Please indicate whether you have **considered** any of the following ***non-treatment decisions*** in the last two weeks.

I considered... [CHECK ALL THAT APPLY]

- | | |
|---|--|
| <input type="checkbox"/> ₁ Whether to change doctors?
<input type="checkbox"/> ₂ Whether to seek second opinion?
<input type="checkbox"/> ₃ Who/what to tell family/friends/children/co-workers?
<input type="checkbox"/> ₄ Who to be around?
<input type="checkbox"/> ₅ Whether to quit work/go back to work? | <input type="checkbox"/> ₆ Whether to go to a support group?
<input type="checkbox"/> ₇ Whether to quit smoking?
<input type="checkbox"/> ₈ Whether to leave my partner?
<input type="checkbox"/> ₉ End of life decisions?
<input type="checkbox"/> ₁₀ Other, please specify: _____ |
|---|--|

2. Of the ***non-treatment decisions*** that you checked above, what one was the most important to you?

*If you did **not** check any of the decisions above, check here 0 and go to question 6 on the following page.*

*Thinking about that most important ***non-treatment decision*** that you **considered**, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE]*

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult for me to make a choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. It's clear what choice is best for me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. I'm aware of the choices I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I feel I know the relative benefits and risks of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Consulting someone else would be useful in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. I am satisfied that I am adequately informed about the issues important to my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. I need more advice and information about my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. I have access to information on all my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. I have the right amount of support from others in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

If you have **decided** what to do for this ***non-treatment decision*** at this point, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My decision is sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. I am satisfied with my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My decision is the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I am satisfied that my decision was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I feel I have made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Today's date: _____					

Thank you for completing this questionnaire. Please mail it back in the envelope provided. If you have any question please call 1-800-361-5481. Thanks again!

Appendix 8:
2 Month Survey

CHES Project:
Comprehensive Health Enhancement Support System

2-Month Post Test
CHES

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

Below is a list of statements that women with breast cancer have said about the information and support they have received from others. We would like to know about your experiences. Please indicate how frequently each of the following statements are true for you. [CHECK ONE BOX PER LINE]

At this time ...

	Never	Rarely	Sometimes	Often	Always
1. I can get answers to my questions at any time.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I can easily get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I can get information from other women who have had breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Whenever I worry, there is someone I can go to.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I am building a bond with other women with breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I feel stronger knowing there are others in my situation.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I've been getting emotional support from others in my situation.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. It helps me to be able to share my feelings and fears.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I get practical, concrete advice on how to go through my treatment.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. There is no one I can turn to for help when I need it.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. Someone steps in if there are everyday things I can't do because of my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel comfortable discussing my cancer with others.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how frequently each of the following statements are true for you:
[CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Sometimes	Often	Always
1. The help I have received has reduced the burden on my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I have enough information to help my daughter(s).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. My family does not support me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I have the help I need to go on with my life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I feel as though I have the strength to deal with my breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. The information and support I received helped reduce my fear of cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I am not afraid to walk away from treatment if it seems right to me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I am able to understand statistics about breast cancer treatment.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. The information and support I have received have made me less anxious.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I know exactly what it is that I want to learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I can figure out how and where to get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. Health information is more difficult for me to obtain than other types of information.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. I am satisfied with the way I currently learn about health issues.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. I feel that I am in control over how and what I learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

How much do you agree or disagree with the following statements? . [CHECK ONE BOX PER LINE]

At this time I feel I understand ...	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. The effect my treatment will have on my quality of life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. How to deal with breast cancer in my work and with my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. What my treatments will be like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. The Pro's and Con's of various treatment approaches.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. How to know if a health care provider is good.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. How to get through my treatments and their side effects.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. How to get a second opinion if I want one.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. What the side effects of my treatment would be, before I started.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time...	Never	Rarely	Some- times	Often	Always
1. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I feel comfortable in asking the physician or nurse questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I feel confident in making decisions about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I know what questions to ask my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I am able to be assertive with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I have confidence in my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I am comfortable discussing my treatment options with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I can manage my own care and be sure that the right treatment is given.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

For this research on how to help women facing breast cancer, we need to have some idea how you're doing now. Below is a list of things that other women with breast cancer have said. Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

At this time ...	Not at all	A little bit	Some-what	Quite a bit	Very much
1. There are people I could count on for emotional support.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. There are people who will help me evaluate things I'm finding out about my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I am pretty much all alone.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. There are people I could rely on when I need help doing something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. There are people who can help me find out the answers to my questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. There are people who will fill in for me if I am unable to do something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I am able to work (including work in home).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. My work (including work in home) is fulfilling.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I am able to enjoy life "in the moment".	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I am sleeping well.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I am enjoying my usual leisure pursuits.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel sad.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. I feel like my life is a failure.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. I feel nervous.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15. I am worried about dying.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16. I feel like everything is an effort.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17. I am worried that my illness will get worse.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below is a list of statements concerning how you're dealing with breast cancer. Please indicate how much you agree/disagree with each statement. [CHECK ONE BOX PER LINE]

In the past 7 days...		Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1.	I needed more information about breast cancer from the perspective of patients who have been there.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2.	I needed more understandable information about breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3.	I needed more information about the latest breast cancer research.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4.	I needed more contact with people who understood what I was going through.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5.	I needed help making decisions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6.	I understood what my doctor told me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7.	I was confident that I could have a positive effect on my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8.	I set some definite goals to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9.	I actively worked to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below is a list of statements concerning the amount of information about breast cancer you feel you need. Please indicate how true each statement has been for you.. [CHECK ONE BOX PER LINE]

In the past 7 days...		Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1.	I wanted health information that I didn't know how to get.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2.	I needed health information that I couldn't afford the time or effort to get.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3.	I needed health information that I couldn't afford to pay for	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

During the past 7 days...

	Does not apply	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I was short of breath.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. I was self-conscious about the way I dress.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. I was bothered by swollen or tender arms.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. I felt sexually attractive.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. I worried about the risk of cancer in other family members.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. I worried about the effect of stress on my illness.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7. My change in weight bothered me.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. My hair loss bothered me.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I am able to feel like a woman.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. My skin bothered me as a result of radiation treatment.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11. I was fatigued.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

For the question below, please check the box which best describes how you have been feeling in the last week. In general, would you say you have been: [CHECK ONLY ONE BOX]

- ☐₁ Feeling normal with no complaints and able to carry on your usual activities
- ☐₂ Performing normal activities with some effort and minor signs of illness
- ☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime
- ☐₄ Disabled, requiring special care and assistance in most activities and in bed more than 50% of the daytime, but not all day
- ☐₅ Very sick, hospitalized for some time or in bed all of the time

Please check how much you agree or disagree with the following statements [CHECK ONE BOX PER LINE]

During the past 7 days...

Disagree very much Disagree Neither Agree nor Disagree Agree Agree very much

1. It was difficult for me to find effective solutions for health problems that came my way. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

2. I handled myself well with respect to my health. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

3. I succeeded in the projects I undertook to improve my health. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

4. I was generally able to accomplish my goals with respect to my health. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

5. I found the efforts to change things I didn't like about my health were ineffective. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

6. I was able to do things for my health as well as most other people. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

In general...

7. My plans for my health don't work out well. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

8. No matter how hard I try, my health doesn't turn out the way I would like. ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

The items below deal with ways you have been coping with the stress in your life since you found out you have breast cancer. Different people deal with stress in different ways. We are interested in how you have tried to deal with stress. Don't answer on the basis of whether or not it seems to be working or not – just whether or not you're doing it. [CHECK ONE BOX PER LINE]

In the past 2 weeks ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. I've been trying to see breast cancer in a different light, to make it seem more positive.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. I've been criticizing myself.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. I've been looking for something good in what is happening.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. I've been making jokes about breast cancer.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. I've been doing something to think about breast cancer less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7. I've been trying to find comfort in my religion or spiritual beliefs.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. I've been blaming myself for things that happened.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I've been praying or meditating.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. I've been making fun of the situation.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11. I have been helping other women with breast cancer.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

TREATMENT DECISIONS

1. Check the box that best describes how you would like to make important treatment decisions:
[CHECK ONLY ONE BOX]

- ☐₁ I prefer to make the decision about my treatment myself
- ☐₂ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion
- ☐₃ I prefer that my doctor & I share responsibility for deciding which treatment is best for me.
- ☐₄ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.
- ☐₅ I prefer to leave all decisions regarding treatment to my doctor.

2. Please indicate if, during the last two weeks, you (and/or your doctors) have considered whether or not to have any of the following treatments.

In the last 2 weeks I considered... [CHECK ALL THAT APPLY]

- ☐₁ Fine needle biopsy
- ☐₂ Lumpectomy versus mastectomy
- ☐₃ What to radiate (e.g., axillary *or* underarm lymph nodes)
- ☐₄ Breast reconstruction
- ☐₅ Type of reconstruction
- ☐₆ Timing of reconstruction
- ☐₇ Lymph node sampling
- ☐₈ How many lymph nodes to sample
- ☐₉ Chemotherapy
- ☐₁₀ Type of chemotherapy
- ☐₁₁ Length of chemotherapy
- ☐₁₂ Bone marrow transplant
- ☐₁₃ Oophorectomy (ovary removal)
- ☐₁₄ Tamoxifen
- ☐₁₅ Clinical trial participation
- ☐₁₆ Immunotherapy
- ☐₁₇ Alternative treatments
- ☐₁₈ Stopping treatment
- ☐₁₉ Other, please specify: _____

3. Of the decisions that you checked above, what one was the most important to you? _____
If you did **not** check any of the decisions above, check here ☐ and go to the top of page 11.

Thinking about the most important treatment decision you considered, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX PER LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult to make a choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. It's clear what choice is best for me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. I'm aware of the choices I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I know the relative benefits of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I know the relative risks and side effects of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. The information I have to make this decision is easy to understand.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. I have no problem using the information I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Consulting someone else would have been useful in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. I am satisfied that I am adequately informed about the issues important to my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. I need more advice and information about my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. I have access to information on all my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

If you have decided what to do for this decision at this point, please indicate how much you agree/disagree with the following statements. Otherwise please go to the beginning of page 11.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My treatment choice is sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. I am satisfied with my treatment choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My treatment choice is the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I am satisfied that my treatment choice was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I feel I have made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

NON-TREATMENT DECISIONS

1. Please indicate whether you have **considered** any of the following **non-treatment decisions** in the last two weeks.

I considered... [CHECK ALL THAT APPLY]

- | | |
|--|---|
| <input type="checkbox"/> ₁ Whether to change doctors? | <input type="checkbox"/> ₆ Whether to go to a support group? |
| <input type="checkbox"/> ₂ Whether to seek second opinion? | <input type="checkbox"/> ₇ Whether to quit smoking? |
| <input type="checkbox"/> ₃ Who/what to tell family/friends/
children/co-workers? | <input type="checkbox"/> ₈ Whether to leave my partner? |
| <input type="checkbox"/> ₄ Who to be around? | <input type="checkbox"/> ₉ End of life decisions? |
| <input type="checkbox"/> ₅ Whether to quit work/go back to work? | <input type="checkbox"/> ₁₀ Other, please specify: _____ |

2. Of the **non-treatment decisions** that you checked above, what one was the most important to you?

If you did **not** check any of the decisions above, check here ☐ and go to question 1 on the middle of page 12.

Thinking about that most important **non-treatment decision** that you **considered**, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. It is difficult for me to make a choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. It's clear what choice is best for me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. I'm aware of the choices I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I feel I know the relative benefits and risks of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Consulting someone else would be useful in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. I am satisfied that I am adequately informed about the issues important to my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. I need more advice and information about my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. I have access to information on all my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. I have the right amount of support from others in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

If you have **decided** what to do for this **non-treatment decision** at this point, please indicate how much you agree/disagree with the following statements. [CHECK ONE BOX ON EACH LINE].

(If you have not decided what to do for this non-treatment decision, please skip the next five questions and go to question 1 in the middle of this page).

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
10. My decision is sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. I am satisfied with my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12. My decision is the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13. I am satisfied that my decision was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14. I feel I have made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

For each of the following questions, please check the box for the answer that comes closest to the way you have been feeling during the past month. [CHECK ONE BOX PER LINE]

"Because of breast cancer, during the past month I felt ..."

	Never	Rarely	Sometimes	Often	Always
1. Helpless	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Tense	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Loved/Cared for	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. Angry	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Hopeless	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Worried	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. Supported	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Frustrated	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. Sad	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. Anxious	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Use the table below to describe your **in-person visits over the last two months** to various health care providers. In each row is a different kind of health care provider, and the columns are number of visits, length of visit, and overall satisfaction. If you haven't used a certain kind of health care provider in the last two months, leave the whole row blank. We've filled in a sample in the first row to show you how someone might answer. Do not include the time you may have spent overnight in the hospital or for day surgeries in this table. Hospitalizations and surgeries will be covered on the following page.

IN-PERSON VISITS TO HEALTH CARE PROVIDERS

	Number of times you visited in the last 2 months	Average amount of time you spent with providers (specify minutes or hours)*	Overall, how satisfied were you with visits to this provider? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Example	2 visits	30 minutes	4
Primary Doctor (e.g. Internist) - NOT Breast Cancer Specialist			
Surgeon			
Plastic Surgeon			
Radiologist			
Oncologist			
Mental Health Provider (e.g. psychologist, counselor, therapist)			
Other Specialty Clinic (dermatologist, etc.)			
Outpatient Lab Visit (e.g. blood test, x-ray, etc.)			
Emergency Room			
Non-Medical Doctor Office (e.g. osteopath, chiropractor)			
Dental Clinic (dentist, oral surgeon, etc.)			
Alternative Care Provider (e.g. massage, acupuncture, etc.)			
Telephone consultations			

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Use the table below to describe your **hospital visits (either overnight stays or day surgeries)** over the last two months. In the first column is the type of care (day surgery, overnight hospital stays). The next column asks for reason for stay (such as mastectomy, etc). Then fill in length of stays (# hours or days), and finally your overall satisfaction with the care you received. If you have not had any day surgeries or overnight hospital stays in the last 2 months skip to question #1 on this same page.

OVERNIGHT HOSPITAL VISITS AND DAY SURGERIES

DURING THE LAST 2 MONTHS...	Reasons for day surgery or overnight hospitalization (e.g. lumpectomy, mastectomy...)	Number of hours (if day surgery), or number of days (if overnight stays)	Overall, how satisfied were you with your care? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Day Surgery (not overnight stays)			
Overnight Hospital Stays			

Think about **all your health care during the past two months** (doctors, dentists, hospitals, therapists, emergency rooms). Mark whether you agree or disagree with the following statements. [CHECK ONE BOX PER LINE]

In the past 2 months...	Disagree very much	Disagree	Neither Agree nor Disagree	Agree	Agree very much
1. I thought about what was going to happen ahead of time.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I felt comfortable with how actively I participated in my care	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please answer the following questions:

3. Today's date: _____

4. Your age: _____

5. Racial/Ethnic Heritage:

☐ 1 African American

☐ 3 Caucasian

☐ 5 Native American Indian

☐ 2 Asian

☐ 4 Latina/Mexican American

☐ 6 Other _____

6. *What type of health insurance coverage do you have (include coverage obtained through a spouse or relative)? [CHECK ALL THAT APPLY]*

- ☐₁ Private group insurance (through you/spouse's employer, union or trade group)
- ☐₂ Individual policy
- ☐₃ Medicaid (also called Title 19 or Medical Assistance)
- ☐₄ Medicare, Part A (pays for hospital bills)
- ☐₅ Medicare, Part B (pays for doctor's bills)
- ☐₆ Medigap policy (supplementary private insurance to Medicare)
- ☐₇ CHAMPUS or CHAMPVA
- ☐₈ Other: _____
- ☐₉ No insurance

7. *Please indicate the highest education level that you have completed.* [CHECK ONE BOX]

- ☐₁ Some junior high/middle school
- ☐₂ Some high school
- ☐₃ High School degree
- ☐₄ Some college courses
- ☐₅ Associate or Technical degree (2 year college)
- ☐₆ Bachelor's degree (4 year college)
- ☐₇ Graduate degree

8. *With whom do you currently live? [CHECK ALL THAT APPLY].*

- ☐₁ I live by myself
- ☐₂ I live with my partner (husband, lover)
- ☐₃ I live with one or more dependent children,
Please list ages and sex of dependent children _____
- ☐₄ I live with one or both of my parents
- ☐₅ I live with other family members
- ☐₆ I live with a friend or friends
- ☐₇ Other, please specify _____

9. *What was your total household income from all sources last year? [CHECK ONE BOX]*

- ☐₁ Less than \$10,000
- ☐₂ \$10,000 - \$19,999
- ☐₃ \$20,000 - \$39,999
- ☐₄ \$40,000 - \$59,999
- ☐₅ \$60,000 or more

10. *When was your breast cancer first diagnosed (give approximate date):* _____

11. *Has your breast cancer spread (metastasized) to other parts of your body other than your lymph nodes?*

- ☐₀ No
- ☐₁ Yes, when did you learn this (give approximate date): _____

12. *Have you had a recurrence of your breast cancer?*

☐₀ No

☐₁ Yes, when did you learn this (give approximate date): _____

13. *What is the stage of your cancer?*

☐₀ Stage 0

☐₁ Stage 1

☐₂ Stage 2

☐₃ Stage 3

☐₄ Stage 4

☐₅ Inflammatory

☐₆ Don't Know

☐₇ Other _____

14. Do you have any other major illnesses or conditions (e.g., diabetes, high blood pressure, heart disease, extremely overweight, history of other cancer, etc.)?

☐₀ No

☐₁ Yes, please list your other major illnesses or conditions:

15. *What is your menopausal status?*

☐₁ Pre-Menopausal

☐₂ Peri-Menopausal

☐₃ Post-Menopausal

16. Write in the actual or scheduled dates for surgeries that you have completed, and those that you have scheduled. Also mark any other surgeries you are considering.

	Start Date (give approximate date):	Considering
• Radical mastectomy	_____	<input type="checkbox"/>
• Modified radical mastectomy	_____	<input type="checkbox"/>
• Lumpectomy	_____	<input type="checkbox"/>
• Breast reconstruction	_____	<input type="checkbox"/>
• Oophorectomy (ovary removal)	_____	<input type="checkbox"/>
• Prophylactic (preventive) mastectomy of unaffected breast:	_____	<input type="checkbox"/>
• Other _____	_____	<input type="checkbox"/>

17. For each of the following breast cancer treatments, give the approximate starting and ending dates, or mark the box if you are seriously considering it. Give dates if you have done it, are doing it, or are planning a treatment.

	Start Date (give approximate dates):	End Date	Considering
• Chemotherapy	_____	_____	<input type="checkbox"/>
• Radiation	_____	_____	<input type="checkbox"/>
• Hormone Therapy (Tamoxifen, Halotestin)	_____	_____	<input type="checkbox"/>
• High Dose Chemo or Bone Marrow Transplant	_____	_____	<input type="checkbox"/>
• Other _____	_____	_____	<input type="checkbox"/>

18. In addition to your prescribed treatments, what else are you doing for your breast cancer (diet, homeopathy, acupuncture, therapeutic touch, etc.)? Please list below:

In the last two months how **EASY WAS IT FOR YOU TO GET** information about breast cancer from the following: [CHECK ONE BOX PER LINE]

	VERY DIFFICULT	DIFFICULT	NEITHER EASY NOR DIFFICULT	EASY	VERY EASY
10A Books or articles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10B Audio or video tapes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10C Doctors or nurses	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10D Other Patients	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10E Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10F The Internet	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10G CHESS	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

In the last two months **HOW MUCH DID YOU USE** the following resources to get information about breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	ATLEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
11A Books or articles	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11B Audio or video tapes	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11C Doctors or nurses	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11D Other Patients	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11E Family or friends	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11F The Internet	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11G CHESS	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

HOW USEFUL were each of the following in regards to information about breast cancer?
[CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
12A Books or articles	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12B Audio or video tapes	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12C Doctors or nurses	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12D Other Patients	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12E Family or friends	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12F The Internet	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12G CHESS	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

In the last two months **HOW USEFUL** were each of the following in terms of **MAKING A DECISION** in regards to breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
13A Books or articles	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13B Audio or video tapes	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13C Doctors or nurses	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13D Other Patients	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13E Family or friends	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13F The Internet	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13G CHESS	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Please rate how **USEFUL** each of the following resources was in getting **EMOTIONAL SUPPORT**.

[CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
14A Books or articles	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14B Audio or video tapes	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14C Doctors or nurses	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14D Other Patients	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14E Family or friends	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14F The Internet	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14G CHESS	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

In the last two months **HOW MUCH HAVE YOU USED** the following resources to help you get **EMOTIONAL SUPPORT**? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	AT LEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
15A Books or articles	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15B Audio or video tapes	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15C Doctors or nurses	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15D Other Patients	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15E Family or friends	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15F The Internet	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15G CHESS	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

We have included a picture of the CHES Services Menu in order to refresh your memory about the various services in CHES. Please indicate how helpful each of the following CHES services are to you.

Overall, how useful are each of the following CHES services? [CHECK ONE BOX PER LINE]

	Not at all	A little bit	Some- what	Quite a bit	Very much
1 Overview of Breast Cancer	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
<u>Decision and Planning Guide</u>					
2 Decisions Notebook (within Decisions, Decisions)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3 Learning from others (within Decisions, Decisions)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4 Action Plan	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5 Consumer Guide	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6 Resource Directory	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
<u>Personal Space</u>					
7 Health Tracking	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8 Assessments	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9 Journaling	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
<u>What's New</u>					
10 CHES News	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11 News Items	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
<u>Reading Room</u>					
12 Questions and Answers	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
13 Instant Library	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Overall, how useful are each of the following *CHESS* services? [CHECK ONE BOX PER LINE]

	Not at all	A little bit	Some- what	Quite a bit	Very much
<u>Other Sites</u>					
14 Web Links	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
15 Medline	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
16 Evaluating Web Info	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
<u>Connecting with Others</u>					
17 Personal Stories	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
18 Discussion Group	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
19 Ask an Expert	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
20 Video Gallery	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
<u>Beginner's Guide</u>					
21 Basic Web Skills	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
22 Getting Started	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
23 About CHESS	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

1. How much does UNDERSTANDING YOUR SITUATION affect your ability to cope with breast cancer?

Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

2 Overall, how much has CHESS helped you to cope with breast cancer?

Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

3 Overall, how much has CHESS helped you in your decision making in regards to breast cancer?

Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

How much do you like each of the following characteristics of *CHESS*? [CHECK ONE BOX PER LINE]

	Not at all	A little bit	Some- what	Quite a bit	Very much
1 I can get information	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2 I can analyze situations	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3 I can communicate with others	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4 The information is up to date	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5 The information is trustworthy	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6 I can find information easily	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7 I got frustrated by how long it took for the information to appear on the screen (download time)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

How much do you like each of the following characteristics of the Internet? [CHECK ONE BOX PER LINE]

		Not at all	A little bit	Some- what	Quite a bit	Very much
1	I can get information	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2	I can analyze situations	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3	I can communicate with others	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4	The information is up to date	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5	The information is trustworthy	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6	I can find information easily	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7	I got frustrated by how long it took for the information to appear on the screen (download time)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

1 What do you like MOST about CHESS?

2 What do you like LEAST about CHESS?

3 How has CHESS helped you deal with your breast cancer?

4 How has CHESS changed your use of health care services?

5 What difference has CHESS made?

6 What else should CHESS have in it?

7 What were the things that interfered with or prevented you from using CHESS more?

8 What else would you like to tell us?

Thank you very much for taking the time to fill out this survey. Please mail it back in the self addressed stamped envelope provided with this survey. If you have any questions feel free to call 1-800-361-5481.

Appendix 9:
4 Month Survey

CHES Project:

Comprehensive Health Enhancement Support System

**4-Month Post Test
CHES**

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

Below is a list of statements that women with breast cancer have said about the information and support they have received from others. We would like to know about your experiences. Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Some- times	Often	Always
1. I can get answers to my questions at any time.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I can easily get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I can get information from other women who have had breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Whenever I worry, there is someone I can go to.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I am building a bond with other women with breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I feel stronger knowing there are others in my situation.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I've been getting emotional support from others in my situation.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. It helps me to be able to share my feelings and fears.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I get practical, concrete advice on how to go through my treatment.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. There is no one I can turn to for help when I need it.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. Someone steps in if there are everyday things I can't do because of my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel comfortable discussing my cancer with others.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

The next list of statements covers the amount of information about breast cancer you feel you need. Please indicate how true each statement has been for you. [CHECK ONE BOX PER LINE]

In the past 7 days ...	Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1. I wanted health information that I didn't know how to get.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I needed health information that I couldn't afford the time or effort to get.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I needed health information that I couldn't afford to pay for.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how frequently each of the following statements are true for you:
[CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Some- times	Often	Always
1. The help I have received has reduced the burden on my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I have enough information to help my daughter(s).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. My family does not support me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I have the help I need to go on with my life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I feel as though I have the strength to deal with my breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. The information and support I received helped reduce my fear of cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I am not afraid to walk away from treatment if it seems right to me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I am able to understand statistics about breast cancer treatment.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. The information and support I have received have made me less anxious.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I know exactly what it is that I want to learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I can figure out how and where to get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. Health information is more difficult for me to obtain than other types of information.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. I am satisfied with the way I currently learn about health issues.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. I feel that I am in control over how and what I learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

How much do you agree or disagree with the following statements? . [CHECK ONE BOX PER LINE]

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
At this time I feel I understand ...					
1. The effect my treatment will have on my quality of life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. How to deal with breast cancer in my work and with my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. What my treatments will be like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. The Pro's and Con's of various treatment approaches.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. How to know if a health care provider is good.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. How to get through my treatments and their side effects.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. How to get a second opinion if I want one.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. What the side effects of my treatment would be, before I started.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time...	Never	Rarely	Some- times	Often	Always
1. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I feel comfortable in asking the physician or nurse questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I feel confident in making decisions about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I know what questions to ask my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I am able to be assertive with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I have confidence in my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I am comfortable discussing my treatment options with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I can manage my own care and be sure that the right treatment is given.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

For this research on how to help women facing breast cancer, we need to have some idea how you're doing now. Below is a list of things that other women with breast cancer have said. Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

At this time ...

Not at all A little bit Some-what Quite a bit Very much

1.	There are people I could count on for emotional support.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2.	There are people who will help me evaluate things I'm finding out about my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3.	I am pretty much all alone.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4.	There are people I could rely on when I need help doing something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5.	There are people who can help me find out the answers to my questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6.	There are people who will fill in for me if I am unable to do something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7.	I am able to work (including work in home).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8.	My work (including work in home) is fulfilling.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9.	I am able to enjoy life "in the moment".	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10.	I am sleeping well.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11.	I am enjoying my usual leisure pursuits.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12.	I feel sad.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13.	I feel like my life is a failure.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14.	I feel nervous.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15.	I am worried about dying.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16.	I feel like everything is an effort.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17.	I am worried that my illness will get worse.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below is a list of statements concerning how you're dealing with breast cancer. Please indicate how much you agree/disagree with each statement. [CHECK ONE BOX PER LINE]

In the past 7 days ...		Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1.	I needed more information about breast cancer from the perspective of patients who have been there.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2.	I needed more understandable information about breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3.	I needed more information about the latest breast cancer research.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4.	I needed more contact with people who understood what I was going through.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5.	I needed help making decisions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6.	I understood what my doctor told me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7.	I was confident that I could have a positive effect on my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8.	I set some definite goals to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9.	I actively worked to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

For each of the following questions, please check the box for the answer that comes closest to the way you have been feeling during the past month. [CHECK ONE BOX PER LINE]

"Because of breast cancer, during the past month I felt ..."

	Never	Rarely	Sometimes	Often	Always
1. Helpless	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Tense	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Loved/Cared for	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. Angry	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Hopeless	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Worried	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. Supported	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Frustrated	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. Sad	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. Anxious	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

During the past 7 days...

	Does not apply	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I was short of breath.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. I was self-conscious about the way I dress.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. I was bothered by swollen or tender arms.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. I felt sexually attractive.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. I worried about the risk of cancer in other family members.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. I worried about the effect of stress on my illness.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7. My change in weight bothered me.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. My hair loss bothered me.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I was able to feel like a woman.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. My skin bothered me as a result of radiation treatments.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11. I was fatigued.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

For the question below, please check the box which best describes how you have been feeling in the last week. In general, would you say you have been: [CHECK ONLY ONE BOX]

- ☐₁ Feeling normal with no complaints and able to carry on your usual activities
- ☐₂ Performing normal activities with some effort and minor signs of illness
- ☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime
- ☐₄ Disabled, requiring special care and assistance in most activities and in bed more than 50% of the daytime, but not all day
- ☐₅ Very sick, hospitalized for some time or in bed all of the time

Please check how much you agree or disagree with the following statements [CHECK ONE BOX PER LINE]

	Disagree very much	Disagree	Neither Agree nor Disagree	Agree	Agree very much
During the past 7 days...					
1. It was difficult for me to find effective solutions for health problems that come my way.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I handled myself well with respect to my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I succeeded in the projects I undertook to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I was generally able to accomplish my goals with respect to my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I found the efforts to change things I didn't like about my health were ineffective.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I was able to do things for my health as well as most other people.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
In general...					
7. My plans for my health don't work out well.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. No matter how hard I try, my health doesn't turn out the way I would like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

On one of the first surveys you filled out, you indicated that you had made the following treatment decision:

We would like to know how you feel about that decision now. Please indicate how much you agree/disagree with the following statements in regards to the above decision. [CHECK ONE BOX PER LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My treatment choice was sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. I am satisfied with my treatment choice I made.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My treatment choice was the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I am satisfied that my treatment choice was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I feel I made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Knowing what I know now, I would still make the same decision today.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

The items below deal with ways you have been coping with the stress in your life since you found out you have breast cancer. Different people deal with stress in different ways. We are interested in how you have tried to deal with stress. Don't answer on the basis of whether or not it seems to be working or not – just whether or not you're doing it. [CHECK ONE BOX PER LINE]

In the past 2 weeks ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. I've been trying see breast cancer in a different light, to make it seem more positive.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. I've been criticizing myself.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. I've been looking for something good in what is happening.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. I've been making jokes about breast cancer.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. I've been doing something to think about breast cancer less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7. I've been trying to find comfort in my religion or spiritual beliefs.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. I've been blaming myself for things that happened.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I've been praying or meditating.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. I've been making fun of the situation.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11. I have been helping other women with breast cancer.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

HEALTH CARE USE AND SATISFACTION

Use the table below to describe your ***in-person visits over the last two months*** to various health care providers. In each row is a different kind of health care provider, and the columns are number of visits, length of visits, and overall satisfaction. If you haven't used a certain kind of health care provider in the last two months, leave the whole row blank. We've filled in a sample in the first row to show you how someone might answer. Do not include the time you may have spent overnight in the hospital or for day surgeries in this table. Hospitalizations and surgeries will be covered on the following page.

IN-PERSON VISITS TO HEALTH CARE PROVIDERS

	Number of times you visited in the last 2 months	Average amount of time you spent with providers (specify minutes or hours)*	Overall, how satisfied were you with visits to this provider? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Example	2 visits	30 minutes	4
Primary Doctor (e.g. Internist) - NOT Breast Cancer Specialist			
Surgeon			
Plastic Surgeon			
Radiologist			
Oncologist			
Mental Health Provider (e.g. psychologist, counselor, therapist)			
Other Specialty Clinic (dermatologist, etc.)			
Outpatient Lab Visit (e.g. blood test, x-ray, mammogram, etc.)			
Emergency Room			
Non-Medical Doctor Office (e.g. osteopath, chiropractor)			
Dental Clinic (dentist, oral surgeon, etc.)			
Alternative Care Provider (e.g. massage, acupuncture, etc.)			
Telephone consultations			

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Use the table below to describe your hospital visits (either overnight stays or day surgeries) over the last two months. In the first column is the type of care (day surgery, overnight hospital stays). The next column asks for reason for stay (such as mastectomy, etc). Then fill in length of stays (# hours or days), and finally your overall satisfaction with the care you received. If you have not had any day surgeries or overnight hospital stays in the last 2 months skip to question #1 on this same page.

OVERNIGHT HOSPITAL VISITS AND DAY SURGERIES

DURING THE LAST 2 MONTHS...	Reasons for day surgery or overnight hospitalization (e.g. lumpectomy, mastectomy...)	Number of hours (if day surgery), or number of days (if overnight stays)	Overall, how satisfied were you with your care? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Day Surgery (not overnight stays)			
Overnight Hospital Stays			

Think about all your health care during the past two months (doctors, dentists, hospitals, therapists, emergency rooms). Mark whether you agree or disagree with the following statements. [CHECK ONE BOX PER LINE]

In the past 2 months...

- | | Disagree
very
much | Disagree | Neither
Agree nor
Disagree | Agree | Agree
very
much |
|--|----------------------------|----------------------------|----------------------------------|----------------------------|----------------------------|
| 1. I thought about what was going to happen ahead of time. | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| 2. I felt comfortable with how actively I participated in my care. | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

Please answer the following questions:

1. Today's date: _____
2. What type of health insurance coverage do you have (include coverage obtained through a spouse or relative)? [CHECK ALL THAT APPLY]
 - ☐ 1 Private group insurance (through you/spouse's employer, union or trade group)
 - ☐ 2 Individual policy
 - ☐ 3 Medicaid (also called Title 19 or Medical Assistance)
 - ☐ 4 Medicare, Part A (pays for hospital bills)
 - ☐ 5 Medicare, Part B (pays for doctor's bills)
 - ☐ 6 Medigap policy (supplementary private insurance to Medicare)
 - ☐ 7 CHAMPUS or CHAMPVA
 - ☐ 8 Other: _____
 - ☐ 9 No insurance

3. *With whom do you currently live?* [CHECK ALL THAT APPLY].

- ☐₁ I live by myself
☐₂ I live with my partner (husband, lover)
☐₃ I live with one or more dependent children,
Please list ages and sex of dependent children _____
☐₄ I live with one or both of my parents
☐₅ I live with other family members
☐₆ I live with a friend or friends
☐₇ Other, please specify _____

4. *Has your breast cancer spread (metastasized) to other parts of your body other than your lymph nodes?*

- ☐₀ No
☐₁ Yes, when did you learn this (give approximate date): _____

5. *Have you had a recurrence of your breast cancer?*

- ☐₀ No
☐₁ Yes, when did you learn this (give approximate date): _____

6. *What is the stage of your cancer?* [CHECK ONE BOX]

- ☐₀ Stage 0
☐₁ Stage 1
☐₂ Stage 2
☐₃ Stage 3
☐₄ Stage 4
☐₅ Inflammatory
☐₆ Other _____
☐₇ Don't Know

7. *Write in the actual or scheduled dates for surgeries that you have completed, and those that you have scheduled. Also mark any other surgeries you are considering.*

	Start Date (give approximate dates):	Considering
• Radical mastectomy	_____	<input type="checkbox"/>
• Modified radical mastectomy	_____	<input type="checkbox"/>
• Lumpectomy	_____	<input type="checkbox"/>
• Breast reconstruction	_____	<input type="checkbox"/>
• Oophorectomy (ovary removal)	_____	<input type="checkbox"/>
• Prophylactic (preventive) mastectomy of unaffected breast:	_____	<input type="checkbox"/>
• Other _____	_____	<input type="checkbox"/>

8. For each of the following breast cancer treatments, give the approximate starting and ending dates, or mark the box if you are seriously considering it. Give dates if you have done it, are doing it, or are planning a treatment.

	Start Date (give approximate dates):	End Date	Considering
• Chemotherapy	_____	_____	<input type="checkbox"/>
• Radiation	_____	_____	<input type="checkbox"/>
• Hormone Therapy (Tamoxifen, Halotestin)	_____	_____	<input type="checkbox"/>
• High Dose Chemo or Bone Marrow Transplant	_____	_____	<input type="checkbox"/>
• Other _____	_____	_____	<input type="checkbox"/>

9. In addition to your prescribed treatments, what else are you doing for your breast cancer (diet, homeopathy, acupuncture, therapeutic touch, etc.)? Please list below:

In the last two months how **EASY WAS IT FOR YOU TO GET** information about breast cancer from the following: [CHECK ONE BOX PER LINE]

	VERY DIFFICULT	DIFFICULT	NEITHER EASY NOR DIFFICULT	EASY	VERY EASY
10A Books or articles	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10B Audio or video tapes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10C Doctors or nurses	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10D Other Patients	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10E Family or friends	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10F The Internet	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10G CHESS	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

In the last two months **HOW MUCH DID YOU USE** the following resources to get information about breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	ATLEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
11A Books or articles	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11B Audio or video tapes	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11C Doctors or nurses	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11D Other Patients	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11E Family or friends	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11F The Internet	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11G CHESS	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

HOW USEFUL were each of the following in regards to information about breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
12A Books or articles	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
12B Audio or video tapes	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
12C Doctors or nurses	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
12D Other Patients	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
12E Family or friends	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
12F The Internet	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
12G CHESS	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

In the last two months **HOW USEFUL** were each of the following in terms of **MAKING A DECISION** in regards to breast cancer? [CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
13A Books or articles	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
13B Audio or video tapes	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
13C Doctors or nurses	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
13D Other Patients	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
13E Family or friends	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
13F The Internet	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
13G CHESS	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Please rate how **USEFUL** each of the following resources was in getting **EMOTIONAL SUPPORT**.

[CHECK ONE BOX PER LINE]

	NOT AT ALL	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
14A Books or articles	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
14B Audio or video tapes	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
14C Doctors or nurses	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
14D Other Patients	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
14E Family or friends	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
14F The Internet	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
14G CHESS	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

In the last two months **HOW MUCH HAVE YOU USED** the following resources to help you get **EMOTIONAL SUPPORT**? [CHECK ONE BOX PER LINE]

	NOT AT ALL	ONCE OR TWICE	ATLEAST ONCE A MONTH	WEEKLY	ALMOST EVERY DAY	EVERY DAY
15A Books or articles	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
15B Audio or video tapes	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
15C Doctors or nurses	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
15D Other Patients	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
15E Family or friends	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
15F The Internet	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
15G CHESS	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

We have included a picture of the CHESS Services Menu in order to refresh your memory about the various services in CHESS. Please indicate how helpful each of the following CHESS services are to you.

Overall, how useful are each of the following CHESS services? [CHECK ONE BOX PER LINE]

Not at all A little bit Some-what Quite a bit Very much

1 Overview of Breast Cancer ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Decision and Planning Guide

2 Decisions Notebook (within Decisions, Decisions) ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

3 Learning from others (within Decisions, Decisions) ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

4 Action Plan ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

5 Consumer Guide ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

6 Resource Directory ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Personal Space

7 Health Tracking ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

8 Assessments ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

9 Journaling ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

What's New

10 CHESS News ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

11

Reading Room

12 Questions and Answers ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

13 Instant Library ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Other Sites

14 Web Links ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

15 Medline ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

16 Evaluating Web Info ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Connecting with Others

17 Personal Stories ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

18 Discussion Group ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

19 Ask an Expert ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

20 Video Gallery ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

Beginner's Guide

21 Basic Web Skills ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

22 Getting Started ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

23 About CHESS ☐₀ ☐₁ ☐₂ ☐₃ ☐₄

1. How much does UNDERSTANDING YOUR SITUATION affect your ability to cope with breast cancer?
 Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so
2. Overall, how much has CHESS helped you to cope with breast cancer?
 Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so
3. Overall, how much has CHESS helped you in your decision making in regards to breast cancer?
 Not at all ☐₀ ☐₁ ☐₂ ☐₃ ☐₄ ☐₅ ☐₆ ☐₇ ☐₈ ☐₉ ☐₁₀ Very much so

How much do you like each of the following characteristics of CHESS? [CHECK ONE BOX PER LINE]

		Not at all	A little bit	Some- what	Quite a bit	Very much
1	I can get information	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2	I can analyze situations	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3	I can communicate with others	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4	The information is up to date	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5	The information is trustworthy	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6	I can find information easily	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7	I got frustrated by how long it took for the information to appear on the screen (download time)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

How much do you like each of the following characteristics of the Internet? [CHECK ONE BOX PER LINE]

		Not at all	A little bit	Some- what	Quite a bit	Very much
1	I can get information	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2	I can analyze situations	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3	I can communicate with others	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4	The information is up to date	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5	The information is trustworthy	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6	I can find information easily	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7	I got frustrated by how long it took for the information to appear on the screen (download time)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

1 What do you like MOST about CHESS?

2 What do you like LEAST about CHESS?

3 How has CHESS helped you deal with your breast cancer?

4 What were the things that interfered with or prevented you from using CHESS more?

5 Has this experience with breast cancer changed you? If so, how?

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Suzy's Story

In the space below, please write what you think about this story. You do not need to summarize it.

Use the following scales to tell us what you think about the research described in the story.
[CHECK ONE BOX PER LINE]

Is it...	Not at all	A little	Some	Pretty much	Very
1. Trustworthy	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. Careful	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. Complete	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Biased/slanted	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. Clear	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. Important	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. Surprising	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

How much did you think about the following things when you read the story: [CHECK ONE BOX PER LINE].

	Not at all	A little	Some	Pretty much	Very
1. What kind of website the story is on.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. Who paid for the survey.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. Who actually did the survey.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Whether the researchers were really scientists.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. Whether the survey had been published.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. Whether the results of the study fit with earlier findings.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. How many people the scientists studied.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. Who the scientists studied.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. Whether the reporter's ideas about the results were right.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Think about your use of the world wide web for health or science information. How much do you agree or disagree with the following statements. [CHECK ONE BOX PER LINE].
(If you have not used the Web for health or science information, you are finished – Thank you!)

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I think about whether an expert on a website is an expert.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
2. I think about whether to trust the information on a website.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
3. I think about how to tell if the website is really a commercial for a product.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
4. I think about who pays for the website when I look at it.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
5. I think about whether the research study can really support what a reporter is saying about it.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
6. I think about what a breast cancer study's results mean.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
7. I think about whether a study's results can be trusted.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
8. I think about whether a journalist who is describing the study really understands it.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
9. I think about whether I should believe a study if the results are new or surprising.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10. I think about what I've heard before on an issue before I believe the results of a new study.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11. I'm skeptical when I hear claims about breast cancer that contradict what I've heard before.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
12. I think about whether the people studied in breast cancer research are enough like me.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
13. I discount research that doesn't rely on a scientifically selected sample of people.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
14. I think about whether the research conclusions are based on a few personal experiences.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
15. When I read about cancer risks, I think about whether I am at risk and how much.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
16. I think about what I need to do to reduce my risk of getting cancer.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
17. I know how to understand most information graphics.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
18. I am comfortable when data are presented in percents..	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Thank you for completing this survey. Please send it back in the self addressed stamped envelope provided. If you have any questions call 1-800-361-5481. Thanks again!

Appendix 10:
9 Month Survey

CHES Project:
Comprehensive Health Enhancement Support System

9-Month Post Test

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

Below is a list of statements that women with breast cancer have said about the information and support they have received from others. We would like to know about your experiences. Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Sometimes	Often	Always
1. I can get answers to my questions at any time.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I can easily get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I can get information from other women who have had breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Whenever I worry, there is someone I can go to.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I am building a bond with other women with breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I feel stronger knowing there are others in my situation.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I've been getting emotional support from others in my situation.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. It helps me to be able to share my feelings and fears.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I get practical, concrete advice on how to go through my treatment.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. There is no one I can turn to for help when I need it.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. Someone steps in if there are everyday things I can't do because of my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel comfortable discussing my cancer with others.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

The next list of statements covers the amount of information about breast cancer you feel you need. Please indicate how true each statement has been for you. [CHECK ONE BOX PER LINE]

In the past 7 days ...	Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1. I wanted health information that I didn't know how to get.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I needed health information that I couldn't afford the time or effort to get.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I needed health information that I couldn't afford to pay for.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how frequently each of the following statements are true for you:
[CHECK ONE BOX PER LINE]

At this time ...	Never	Rarely	Some- times	Often	Always
1. The help I have received has reduced the burden on my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I have enough information to help my daughter(s).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. My family does not support me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I have the help I need to go on with my life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I feel as though I have the strength to deal with my breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. The information and support I received helped reduce my fear of cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I am not afraid to walk away from treatment if it seems right to me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I am able to understand statistics about breast cancer treatment.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. The information and support I have received have made me less anxious.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I know exactly what it is that I want to learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I can figure out how and where to get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. Health information is more difficult for me to obtain than other types of information.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. I am satisfied with the way I currently learn about health issues.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. I feel that I am in control over how and what I learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

How much do you agree or disagree with the following statements? . [CHECK ONE BOX PER LINE]

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
At this time I feel I understand ...					
1. The effect my treatment will have on my quality of life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. How to deal with breast cancer in my work and with my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. What my treatments will be like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. The Pro's and Con's of various treatment approaches.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. How to know if a health care provider is good.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. How to get through my treatments and their side effects.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. How to get a second opinion if I want one.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. What the side effects of my treatment would be, before I started.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how frequently each of the following statements are true for you: [CHECK ONE BOX PER LINE]

At this time...	Never	Rarely	Some- times	Often	Always
1. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I feel comfortable in asking the physician or nurse questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I feel confident in making decisions about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I know what questions to ask my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I am able to be assertive with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I have confidence in my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I am comfortable discussing my treatment options with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I can manage my own care and be sure that the right treatment is given.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

For this research on how to help women facing breast cancer, we need to have some idea how you're doing now. Below is a list of things that other women with breast cancer have said. Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

At this time ...	Not at all	A little bit	Some-what	Quite a bit	Very much
1. There are people I could count on for emotional support.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. There are people who will help me evaluate things I'm finding out about my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I am pretty much all alone.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. There are people I could rely on when I need help doing something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. There are people who can help me find out the answers to my questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. There are people who will fill in for me if I am unable to do something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I am able to work (including work in home).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. My work (including work in home) is fulfilling.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I am able to enjoy life "in the moment".	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I am sleeping well.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I am enjoying my usual leisure pursuits.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I feel sad.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. I feel like my life is a failure.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. I feel nervous.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15. I am worried about dying.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16. I feel like everything is an effort.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17. I am worried that my illness will get worse.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below is a list of statements concerning how you're dealing with breast cancer. Please indicate how much you agree/disagree with each statement. [CHECK ONE BOX PER LINE]

In the past 7 days ...	Disagree very much	Disagree	Neither agree nor disagree	Agree	Agree very much
1. I needed more information about breast cancer from the perspective of patients who have been there.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I needed more understandable information about breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I needed more information about the latest breast cancer research.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I needed more contact with people who understood what I was going through.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I needed help making decisions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I understood what my doctor told me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I was confident that I could have a positive effect on my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I set some definite goals to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I actively worked to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

For each of the following questions, please check the box for the answer that comes closest to the way you have been feeling during the past month. [CHECK ONE BOX PER LINE]

"Because of breast cancer, during the past month I felt ..."

	Never	Rarely	Sometimes	Often	Always
1. Helpless	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Tense	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Loved/Cared for	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. Angry	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Hopeless	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Worried	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. Supported	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Frustrated	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. Sad	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. Anxious	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Please indicate how true each statement is for you. [CHECK ONE BOX PER LINE]

During the past 7 days...

	Does not apply	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I was short of breath.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. I was self-conscious about the way I dress.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. I was bothered by swollen or tender arms.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. I felt sexually attractive.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. I worried about the risk of cancer in other family members.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. I worried about the effect of stress on my illness.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7. My change in weight bothered me.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. My hair loss bothered me.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I was able to feel like a woman.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. My skin bothered me as a result of radiation treatments.	<input type="radio"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11. I was fatigued.		<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

For the question below, please check the box which best describes how you have been feeling in the last week.
In general, would you say you have been: [CHECK ONLY ONE BOX]

- ☐₁ Feeling normal with no complaints and able to carry on your usual activities
- ☐₂ Performing normal activities with some effort and minor signs of illness
- ☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime
- ☐₄ Disabled, requiring special care and assistance in most activities and in bed more than 50% of the daytime, but not all day
- ☐₅ Very sick, hospitalized for some time or in bed all of the time

Please check how much you agree or disagree with the following statements [CHECK ONE BOX PER LINE]

	Disagree very much	Disagree	Neither Agree nor Disagree	Agree	Agree very much
During the past 7 days...					
1. It was difficult for me to find effective solutions for health problems that come my way.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I handled myself well with respect to my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I succeeded in the projects I undertook to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I was generally able to accomplish my goals with respect to my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I found the efforts to change things I didn't like about my health were ineffective.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I was able to do things for my health as well as most other people.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
In general...					
7. My plans for my health don't work out well.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. No matter how hard I try, my health doesn't turn out the way I would like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

On one of the first surveys you filled out, you indicated that you had made the following treatment decision:

We would like to know how you feel about that decision now. Please indicate how much you agree/disagree with the following statements in regards to the above decision. [CHECK ONE BOX PER LINE]

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1. My treatment choice was sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. I am satisfied with my treatment choice I made.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. My treatment choice was the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. I am satisfied that my treatment choice was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. I feel I made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Knowing what I know now, I would still make the same decision today.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

The items below deal with ways you have been coping with the stress in your life since you found out you have breast cancer. Different people deal with stress in different ways. We are interested in how you have tried to deal with stress. Don't answer on the basis of whether or not it seems to be working or not – just whether or not you're doing it. [CHECK ONE BOX PER LINE]

In the past 2 weeks ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. I've been trying see breast cancer in a different light, to make it seem more positive.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. I've been criticizing myself.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. I've been looking for something good in what is happening.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. I've been making jokes about breast cancer.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. I've been doing something to think about breast cancer less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7. I've been trying to find comfort in my religion or spiritual beliefs.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. I've been blaming myself for things that happened.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
9. I've been praying or meditating.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. I've been making fun of the situation.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
11. I have been helping other women with breast cancer.	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

HEALTH CARE USE AND SATISFACTION

Use the table below to describe your **in-person visits over the last two months** to various health care providers. In each row is a different kind of health care provider, and the columns are number of visits, length of visits, and overall satisfaction. If you haven't used a certain kind of health care provider in the last two months, leave the whole row blank. We've filled in a sample in the first row to show you how someone might answer. Do not include the time you may have spent overnight in the hospital or for day surgeries in this table. Hospitalizations and surgeries will be covered on the following page.

IN-PERSON VISITS TO HEALTH CARE PROVIDERS

	Number of times you visited in the last 2 months	Average amount of time you spent with providers (specify minutes or hours)*	Overall, how satisfied were you with visits to this provider? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Example	2 visits	30 minutes	4
Primary Doctor (e.g. Internist) - NOT Breast Cancer Specialist			
Surgeon			
Plastic Surgeon			
Radiologist			
Oncologist			
Mental Health Provider (e.g. psychologist, counselor, therapist)			
Other Specialty Clinic (dermatologist, etc.)			
Outpatient Lab Visit (e.g. blood test, x-ray, mammogram, etc.)			
Emergency Room			
Non-Medical Doctor Office (e.g. chiropractor)			
Dental Clinic (dentist, oral surgeon, etc.)			
Alternative Care Provider (e.g. massage, acupuncture, etc.)			
Telephone consultations			

*Include time spent with all provider staff (doctors, nurses, pharmacists, etc.)

Use the table below to describe your hospital visits (either overnight stays or day surgeries) over the last two months. In the first column is the type of care (day surgery, overnight hospital stays). The next column asks for reason for stay (such as mastectomy, etc). Then fill in length of stays (# hours or days), and finally your overall satisfaction with the care you received. If you have not had any day surgeries or overnight hospital stays in the last 2 months skip to question #1 on this same page.

OVERNIGHT HOSPITAL VISITS AND DAY SURGERIES

DURING THE LAST 2 MONTHS...	Reasons for day surgery or overnight hospitalization (e.g. lumpectomy, mastectomy...)	Number of hours (if day surgery), or number of days (if overnight stays)	Overall, how satisfied were you with your care? (Use a 1 to 5 scale, 1=very dissatisfied to 5=very satisfied)
Day Surgery (not overnight stays)			
Overnight Hospital Stays			

Think about all your health care during the past two months (doctors, dentists, hospitals, therapists, emergency rooms). Mark whether you agree or disagree with the following statements. [CHECK ONE BOX PER LINE]

In the past 2 months...

- | | Disagree
very
much | Disagree | Neither
Agree nor
Disagree | Agree | Agree
very
much |
|--|----------------------------|----------------------------|----------------------------------|----------------------------|----------------------------|
| 1. I thought about what was going to happen ahead of time. | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |
| 2. I felt comfortable with how actively I participated in my care. | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 |

Please answer the following questions:

1. Today's date: _____
2. What type of health insurance coverage do you have (include coverage obtained through a spouse or relative)? [CHECK ALL THAT APPLY]
 - ☐ 1 Private group insurance (through you/spouse's employer, union or trade group)
 - ☐ 2 Individual policy
 - ☐ 3 Medicaid (also called Title 19 or Medical Assistance)
 - ☐ 4 Medicare, Part A (pays for hospital bills)
 - ☐ 5 Medicare, Part B (pays for doctor's bills)
 - ☐ 6 Medigap policy (supplementary private insurance to Medicare)
 - ☐ 7 CHAMPUS or CHAMPVA
 - ☐ 8 Other: _____
 - ☐ 9 No insurance

3. *With whom do you currently live?* [CHECK ALL THAT APPLY].

- ☐₁ I live by myself
- ☐₂ I live with my partner (husband, lover)
- ☐₃ I live with one or more dependent children,
Please list ages and sex of dependent children _____
- ☐₄ I live with one or both of my parents
- ☐₅ I live with other family members
- ☐₆ I live with a friend or friends
- ☐₇ Other, please specify _____

4. *Has your breast cancer spread (metastasized) to other parts of your body other than your lymph nodes?*

- ☐₀ No
- ☐₁ Yes, when did you learn this (give approximate date): _____

5. *Have you had a recurrence of your breast cancer?*

- ☐₀ No
- ☐₁ Yes, when did you learn this (give approximate date): _____

6. *What is the stage of your cancer?* [CHECK ONE BOX]

- ☐₀ Stage 0
- ☐₁ Stage 1
- ☐₂ Stage 2
- ☐₃ Stage 3
- ☐₄ Stage 4
- ☐₅ Inflammatory
- ☐₆ Other _____
- ☐₇ Don't Know

7. *Write in the actual or scheduled dates for surgeries that you have completed, and those that you have scheduled. Also mark any other surgeries you are considering.*

	Start Date (give approximate dates):	Considering
• Radical mastectomy	_____	<input type="checkbox"/>
• Modified radical mastectomy	_____	<input type="checkbox"/>
• Lumpectomy	_____	<input type="checkbox"/>
• Breast reconstruction	_____	<input type="checkbox"/>
• Oophorectomy (ovary removal)	_____	<input type="checkbox"/>
• Prophylactic (preventive) mastectomy of unaffected breast: _____		<input type="checkbox"/>
• Other _____	_____	<input type="checkbox"/>

8. *For each of the following breast cancer treatments, give the approximate starting and ending dates, or mark the box if you are seriously considering it. Give dates if you have done it, are doing it, or are planning a treatment.*

	Start Date (give approximate dates):	End Date	Considering
• Chemotherapy	_____	_____	<input type="checkbox"/>
• Radiation	_____	_____	<input type="checkbox"/>
• Hormone Therapy (Tamoxifen, Halotestin)	_____	_____	<input type="checkbox"/>
• High Dose Chemo or Bone Marrow Transplant	_____	_____	<input type="checkbox"/>
• Other _____	_____	_____	<input type="checkbox"/>

9. *In addition to your prescribed treatments, what else are you doing for your breast cancer (diet, homeopathy, acupuncture, therapeutic touch, etc.)? Please list below:*

10. *Has this experience with breast cancer changed you? If so, how?*

11. *Is there anything else you would like to tell us?*

Thank you very much for taking part in this study. Your participation in this study will help us better serve women diagnosed with breast cancer in the future. It is our hope that being part of this study has been beneficial to you as well. If you have further comments or suggestions don't hesitate to contact us at 1-800-361-5481.